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Running head: PSYCHOLOGISTS' HOPE FOR RECOVERY

Psychologists' Hope for Recovery at First Diagnosis Schizophrenia: A Training Model

by

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DISSERTATION

Submitted in partial fulfillment for the degree of
Doctor of Psychology in the Department of Clinical Psychology
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**PSYCHOLOGISTS' HOPE FOR RECOVERY AT FIRST DIAGNOSIS
SCHIZOPHRENIA: A TRAINING MODEL**

presented on May 2, 2017

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Abstract

Recovery from schizophrenia is a widely disputed topic among mental health professionals. In spite of scholarly research supporting improved prognosis in schizophrenia, some mental health professionals maintain the belief that recovery from schizophrenia is impossible. A constructionist paradigm frames an understanding of recovery, and describes how different recovery models of schizophrenia may be integrated. From a qualitative approach, this study explores diagnosed individuals' personal accounts of recovery from schizophrenia. Narrative research provides a framework for analyzing first person, written accounts of recovery from schizophrenia from a criterion-based sample of 18 participants. The results of the study provide insight into dynamic understandings of recovery from schizophrenia, the process of recovery, and facilitators of, and barriers to, recovery. Themes emerging from this narrative analysis inform a more integrated training model for clinical psychology graduate trainees.

Keywords: schizophrenia, recovery, consumer/survivor, medical model, narrative analysis, first person account

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Psychologists' Hope for Recovery at First Diagnosis Schizophrenia: A Training Model

This dissertation concerns recovery in schizophrenia, the lack of a consensual definition of recovery from schizophrenia in the field of clinical psychology, and the perspectives of those diagnosed with schizophrenia regarding the recovery process. The overall aim of this study was to construct a theoretically-informed, integrated model of recovery perspectives to: (a) better understand the complexity of the path to, and definition of, recovery in schizophrenia, and (b) provide clinical psychology graduate trainees with a best practice training model for working with individuals diagnosed with schizophrenia. Using a sample of first person accounts of recovery from schizophrenia, this study aimed to narratively analyze, explore, and understand diagnosed individuals' definitions, experiences, and facilitators of the recovery process. The sample of narratives was drawn and selected from a compendium of first person accounts written by individuals diagnosed with schizophrenia. The themes emerging from a narrative analysis of a sample of first person narratives concerning schizophrenia help to inform a more integrated training model.

All too commonly, the term "schizophrenia" is followed by hopeless descriptors in the scholarly literature, such as "severe" (e.g., Honer et al., 2007), "chronic," and "debilitating" (e.g., Ciompi, Harding, & Lehtinen, 2010). The idea of recovery from schizophrenia has a short history, with advocacy for its necessary role in treatment beginning in the 1970s (Frese & Davis, 1997). Since then, recovery has gradually appeared as a possibility for diagnosed individuals (Anthony, 2000). The perception of schizophrenia as a chronic, incurable illness is rooted in its conception, by German psychiatrist Emil Kraepelin in 1899, as *dementia praecox* (Harding, Zubin, & Strauss, 1992), named as such by French psychiatrist, Benedict Augustine Morel (Lavretsky, 2008). At that time, diagnosis was equated with prognosis (Strauss & Carpenter,

1981; Vahia & Cohen, 2008), deeming recovery from schizophrenia to be rare. Thus, schizophrenia was viewed as an illness of deterioration (Vahia & Cohen, 2008). The promotion and maintenance of this depiction may overshadow alternative realities of recovery that include hope and well-being even in the company of symptoms (Corrigan & Ralph, 2005). A pessimistic relationship between diagnosis and prognosis may be one of the many underlying factors preserving professional disbelief in recovery from schizophrenia. Although the intensity of these bleak perceptions of schizophrenia have lessened, and continue to transform (e.g., Corrigan & Ralph, 2005), many mental health professionals (MHPs), including social workers, psychiatric nurses, psychologists, and psychiatrists, still cling to an image of chronicity, progressive deterioration, and hopelessness (Paquette & Navarro, 2005).

Area of Concern

Scholarly research over the past 40 years supports improved prognosis and outcome in individuals diagnosed with schizophrenia (Ciompi et al., 2010; Harding et al., 1992; Silverstein & Bellack, 2008; Warner, 2009; World Health Organization [WHO], 2001), evidenced by longitudinal outcome studies showing significant improvement in, or full remission of, symptoms (e.g., Harding, Brooks, Ashikaga, Strauss, & Breier, 1987). Those MHPs who hold enduring disbelief towards the idea of recovery in schizophrenia have likely overlooked recent literature (McGuire, 2000) documenting improved prognosis and outcomes in schizophrenia, and the possibility of recovery (Harding et al., 1992; Peebles et al., 2007; Warner, 2009). More recent investigations seek to reach a consensual definition of recovery, reflecting both process and outcome-based understandings (e.g., Davidson & Roe, 2007).

In fact, available data do not support the degree of pessimism. The five longitudinal outcome studies of schizophrenia since 1972 found 50% or more of the diagnosed individuals at

20, 30, and 40-year follow-up periods to have significantly improved or completely recovered from schizophrenia (Harding, Zubin, & Strauss, 1987). Additionally, in spite of the WHO's (2001) report stating, "almost half the individuals initially developing schizophrenia can expect a full and lasting recovery," (p. 33) with psychosocial support and pharmacological treatment, the *Diagnostic and Statistical Manual of Mental Disorders, 5th ed.* (DSM-5) reports that only 20% of those diagnosed with schizophrenia will experience a "favorable" course of illness, with a reported small subset of these individuals achieving a full recovery (American Psychiatric Association (APA), 2013, p. 102). The DSM-5 does not provide rationale for this discrepancy in findings; however, APA notes that variability of course and outcome in schizophrenia are still not well understood, making it difficult to predict whether a given individual will recover (APA, 2013).

Outcomes of recovery from schizophrenia in developing countries are even better than outcomes in the United States, and raise consideration of how to improve outcomes further in the U.S. For example, the International Pilot Study of Schizophrenia (IPSS; WHO, 1974, 1979, as cited in Sartorius, Gulbinat, Harrison, Laska, & Siegel, 1996) found that sociocultural setting was the best predictor of outcome from schizophrenia at two and five-year follow-ups (Jablensky, Sartorius, Ernberg, & Anker, 1992): outcomes are better in developing countries (i.e., India, Columbia, and Nigeria) than developed (i.e., United States, the United Kingdom, Russia, and Denmark). At two-year follow-up, 52% of individuals diagnosed with schizophrenia in developing countries fully recovered, compared to 39% of individuals in the developed countries. The five-year follow-up study reported 73% of individuals diagnosed with schizophrenia in the developing countries to recover, compared to 52% of such individuals in developed countries (Leff, Sartorius, Jablensky, Korten, & Ernberg, 1992; Whitaker, 2002). Finally, better outcomes

in developing than developed countries have continued into the 21st century (WHO, 2001).

Factors accounting for improved schizophrenia outcomes in developing versus developed countries, as suggested by IPSS investigators, include “close family ties, extended families, agricultural economy, and active participation of family members in caring for patients who are still under treatment in hospitals” (Tsuang, 1982, p. 205). In a similar vein, Kulhara (1994) proposed un-researched factors that may account for the better schizophrenia outcomes in developing countries, including but not limited to social acceptance for both diagnosed individuals and their families, familial hierarchical structure and interaction patterns, and the degree to which the diagnosed individual perceives he or she is a burden on the family. Additionally, Bhugra (2006) posited that the sociocultural differences in the WHO studies may be explained by less expressed emotion within families and minimal mental illness stigmatization. Notably, little to no use of medication in treatment was also associated with better outcomes in the WHO studies (Hornstein, 2009).

In the five-year WHO follow-up study, the definition of recovery was based on clinical and social outcomes, specifically the presence and degree of psychotic symptoms and level of social functioning (Leff et al., 1992). These findings have met with some criticism. For example, Kulhara (1994) characterized the interrelatedness among the measured outcome variables as one possible flaw. The most frequent criticism of the WHO follow-up outcome studies, however, was of the methodology (Bhugra, 2006), particularly the influence of illness duration at admission on outcome (Tsuang, 1982). Tsuang argued that the methodological concerns made for difficult comparison among independent studies. Because of these methodological problems, the same limitation of results was hypothesized to affect many of the cross-cultural schizophrenia outcome research studies. The major concern was that the participants of the studies in developing

countries were suffering from acute, not chronic, cases of schizophrenia (e.g., Kulhara, 1994); it is well-known that acute schizophrenia has a better prognosis.

Moreover, and particularly salient to the current investigation, difficulties that arise with course and outcome research of schizophrenia more generally include, “the absence of a consensual definition of recovery, variable diagnostic and outcome criteria, and cases lost to follow-up” (Lauronen et al., 2005, p. 375). Thus, some of the interpretive limitations of the international and cross-cultural research also affect studies conducted solely in the US.

Most of the existing outcome data, including some cross-cultural data (e.g., Srivastava, Stitt, Thakar, Shah, and Chinnasamy, 2009), reflect medical model, outcome-based definitions of recovery, where the focus is on symptom amelioration, remission, and reduction. However, these quantitative meanings of recovery are not endorsed consensually within the field of psychology, or by many of the very individuals diagnosed with schizophrenia (Anthony, 1993). Alternative definitions of recovery as applied to mental illness (Jacobson & Curtis, 2006) are emerging from the *consumer/survivor movement* (Frese & Davis, 1997), and *psychiatric rehabilitation* (PR) movement (Anthony, 1993).

These alternative definitions are more aligned with process-based definitions of recovery, where the individual's experience of hope, and self-determination to improve quality of life, are supported and prioritized (Davidson & Roe, 2007; Fisher, 2003; Silverstein & Bellack, 2008). In light of the movements' similarities, it is important to distinguish the nuanced differences between the consumer/survivor and PR views of recovery. Consumers and survivors both view recovery as a display of empowerment and an opportunity to “reclaim one's life, to validate one's self in order that one may be validated as an autonomous, competent individual in the world” (Jacobson & Curtis, 2006, p. 359), while the PR conceptualization of recovery concerns

more of an improvement in, and maintenance of, social and/or occupational functioning (Jacobson & Curtis, 2006).

Although the terms *consumer* and *survivor* are used interchangeably, there are meaningful distinctions. Like survivors, consumers advocate against stigma and discrimination. Unlike survivors, consumers typically view themselves as needing treatment (Frese, 2008) and aim to transform current mental health services in conjunction with MHPs, but do not necessarily oppose or want to abolish the medical model (Hornstein, 2009). In contrast, the National Association of Psychiatric Survivors (NAPS) chose the term survivor, because they saw themselves as “survivors of an overbearingly oppressive” mental health system, comparing themselves to Holocaust survivors (Frese, 2008, p. 301). Central activities of survivors include advocating for their rights as human beings and against involuntary treatment (Frese, 2008). Although survivors are viewed as antipsychiatry activists, there are some survivors who endorse aspects of the medical model (Hornstein, 2009).

By using only medical model definitions of recovery as criteria in the schizophrenia outcome literature, we lose an important insider’s perspective on the meaning of recovery—that of the diagnosed individual (Thornhill, Clare, & May, 2004). As a result of such a crude split in views of recovery, we often see MHPs and diagnosed individuals forced to choose between two recovery categories: one of outcome, and one of process (Silverstein & Bellack, 2008). So then, what does recovery really *mean*? How should it be defined, and who gets to define it? And, what does the process of recovery involve?

Proposed Research Questions

Psychology’s lack of consensual definition of recovery from schizophrenia prompted five research questions that framed the purpose of this study:

1. How do individuals with schizophrenia define and describe the process and facilitators of recovery?
2. In what ways do the recovery processes of individuals with schizophrenia mirror existing (e.g., medical, consumer/survivor) views of recovery? In what ways are they different?
3. What would an integrated model of the recovery process from schizophrenia look like were it to include: (a) best practices offered by each of the existing models of recovery, combined with (b) emergent views of diagnosed individuals?
4. How can a theoretically, integrated recovery model be incorporated into graduate-level clinical training?
5. How could an integrated recovery model be used in practice by MHPs?

Theoretical Framework: Constructionism

Because the process of recovery from schizophrenia is complex and non-linear (Davidson & Roe, 2007; Peer, Kupper, Long, Brekke, & Spaulding, 2007; Spaniol, Wewiorski, Gagne, & Anthony, 2002), the experience of recovery is multi-dimensional (Beeble & Salem, 2009). Thus, binary understandings of recovery (i.e., outcome vs. process) do not offer much insight into the actual process and meaning of recovery. However, the scholarly research of the elements involved in promoting the process of recovery is limited (e.g., Beeble & Salem, 2009; Tooth, Kalyanasundaram, Glover, & Momenzadah, 2003), and such information is required to attain a more comprehensive understanding of recovery (Silverstein & Bellack, 2008). Therefore, I employed constructionism to conceptualize and arrive at a multi-dimensional understanding of recovery from schizophrenia.

The constructionist frame also incorporates aspects of constructivism. The choice to draw

from both paradigms is based on Peterson and Peterson's (1997) observation that constructionism and constructivism seem complementary rather than identical, or conversely, incompatible. As constructionism is concerned with the social and interactive processes by which a phenomenon is understood as real (Gergen, 2009), constructivism concerns the internal capacities (e.g., cognition, awareness of self) of humans that allow them to participate in the constructionist world (Roger Peterson, personal communication, August, 27, 2012). According to Mahoney (1991, 2001), constructivism asserts that humans are actively involved in the creation of their personal realities and experiences of the world. This construction of personal meaning occurs both intrapsychically and through relationship with others (Mahoney, 1991; Peterson & Peterson, 1997). Core beliefs and assumptions influence understandings of the world (Mahoney, 1991) and are ultimately exchanged through dialogue. As a result, knowledge is created through the exchange of multiple sources of data, with particular consideration for the context in which the knowledge is created (Mertens, 2010). The meaning and usefulness of shared language, then, is contained within relationships and determined by the current context (Gergen, 2009). Constructions are accepted as accurate when they achieve *social utility* (Gergen, 2009) and are viewed as useful within the current context. The result of this process is a socially constructed reality (Bloomberg & Volpe, 2012; Gergen, 2009; Mertens, 2010).

Framing these seemingly dichotomous outcome and process models of recovery from a constructionist perspective helps to illuminate how both models are constructions from different and specific social, cultural, and historical traditions (Corrigan & Ralph, 2005; Gergen, 2009; Peterson & Peterson, 1997). In doing so, both understandings of recovery may be acknowledged and respected as different realities of the same phenomenon but not privileged over one another (Peterson & Peterson, 1997), as they may co-exist in an individual's personal understanding and

experience of recovery in schizophrenia (Anthony, 1993). Moreover, research has suggested that receiving treatment consistent with the medical model may influence the degree to which consumers adopt and ascribe personal meaning to recovery oriented-concepts (Silverstein & Bellack, 2008). For example, Resnick, Rosenheck, and Lehman (2004) concluded that the medical model and recovery-oriented notions may be “mutually reinforcing” (p. 546), rather than in opposition, based on the finding that identification with a recovery model was negatively associated with psychiatric symptom severity. In other words, the fact that psychiatric symptoms were commonly treated with medical model interventions suggests a need for integration of the recovery models in treatment, as recovery-oriented notions were positively associated with other beneficial parts of treatment. Conceptualizing recovery as a multifaceted phenomenon may result in improved understanding of the construct (Corrigan & Ralph, 2005). To encompass the heterogeneity in clinical presentation, and course of illness among those with schizophrenia (APA, 2013; Warner, 2009), we need a more complex and comprehensive model of recovery. Approaching the topic in this way sets up a platform to integrate the two existing recovery definitions (Peer et al., 2007).

Davidson, Lawless, and Leary (2005) proposed that both dominant understandings of recovery “are useful for different purposes and populations...the synthesis of the two will offer a broader perspective on life with, after, or despite mental illness” (p. 664). Given that an individual with schizophrenia may experience both the outcome and process models simultaneously within recovery (Davidson & Roe, 2007), a constructionist frame would encourage the exploration, acceptance, and understanding of both recovery processes. Constructivism supports the phenomenon of recovery as a dynamic, complex, and multi-storied process by asserting that the ability of humans to subjectively make meaning out of their own

personal experiences inevitably results in a narrative of multiple meanings (Bloomberg & Volpe, 2012).

Promoting multiple interpretations of recovery is necessary for coming to a more consensual and integrated agreement about recovery in mental illness (Davidson & Roe, 2007), and has implications for improving treatment outcomes, the therapeutic alliance, and quality of life for the consumer. Adopting a recovery orientation to treatment requires MHPs to step out of their “expert” roles and enter into more collaborative relationships with their clients diagnosed with schizophrenia. Supporting this notion is Hornstein’s (2009) assertion that “first person experience is crucial to understanding madness and its treatment” (p. xxii).

Significance

Several significant and transformative implications for the field of clinical psychology may arise from the current exploration. These areas of importance include reclaiming diagnosis apart from prognosis, moving towards an integrated model of recovery, and eroding stigma with opportunities for advocacy. First, reclaiming diagnosis, apart from prognosis, has implications for intervention and treatment outcomes for all individuals diagnosed with schizophrenia. Second, moving towards an integrated model of recovery involves viewing recovery with a comprehensive, multi-storied lens; which may offer clients more alternatives of hope and outcome. More importantly, an integrated model communicates the notion that there are options (Anthony, 1993). An integrated model would also allow for consideration of treating certain phases of the recovery process (Peer et al., 2007; Schrank & Slade, 2007; Spaniol et al., 2002). Third, if new, integrated understandings of recovery can erode previously-held stigmatizing and negative attitudes towards recovery; MHPs would be in better positions to advocate for, and even help create, programs that discourage stigmatization and discrimination against individuals with

schizophrenia, empowering recovery according to the consumer/survivor model (Bellack, 2006).

Why Now?

There are several, key reasons for studying recovery in schizophrenia *now*. First, although recovery-oriented systems of care are increasingly being developed, the effectiveness of these systems is hampered by both a continued absence of a consensual definition of recovery, and a comprehensive understanding of the complexity of the process (Silverstein & Bellack, 2008). Second, the implementation of recovery-oriented systems of care needs to occur on a national level. William Anthony, commonly known for his writings on recovery in SMI, asserted that, “recovery still just remains a vision,” in spite of its role in some mental health care changes in the last 20 years (Hanlon, 2014, p. 1). Anthony described many individual/local efforts to restructure service delivery, according to a recovery-oriented treatment framework. However, national changes need to be implemented in the mental health system to ignite a paradigm shift (Hanlon, 2014). A recovery-oriented system of care is a paradigm shift in mental health services, based on the belief that recovery from mental illness is possible. The mental health system of the 20th century rested on the assumption that individuals did not recover from mental illness, and only maintained a compromised level of functioning or deteriorated (Anthony, 2000). Additionally, this paradigm requires the mental health system to share power and responsibility with system users. The organizing principles underpinning mental health services have to be reformulated, not merely re-labeled as “recovery-oriented” (Jacobson & Curtis, 2006).

Third, a paradigm shift in service delivery needs to reflect the importance and necessity of providing those with SMIs the opportunity *to* recover, rather than question whether individuals *can* recover. An assumption of this research was, therefore, not to question whether or not to offer psychosocial rehabilitation and community support to individuals with SMIs, but

to question how to efficaciously implement these services for diagnosed individuals (Anthony, 1991). Most fundamental to this exploration was my assumption that everyone deserves, and has the inalienable right, to recover.

Critical Literature Review

In this critical review of the literature, I discussed the following topics pertinent to our current understandings of recovery from schizophrenia: (a) a brief history and evolution of schizophrenia in the United States, including etiological theories; (b) outcome-based recovery definitions; (c) process-based recovery definitions; (d) opportunities for bridging process and outcome models; (e) facilitators of recovery; (f) doctoral training models for SMI; and (g) qualitative research exploring the process of recovery.

A Review of Schizophrenia

Schizophrenia is an SMI characterized by the presence of *delusions*, *hallucinations*, and/or *disorganized speech* and may include *grossly disorganized or catatonic behavior* and/or *negative symptoms* (APA, 2013). To meet DSM-5 criteria for a diagnosis of schizophrenia, at least two of the aforementioned symptoms must be present for a significant portion of a one-month period, and at least one of those two symptoms must be of the first aforementioned three. Additionally, there must be a decrease in level of functioning in one or more major life areas (i.e., occupational, interpersonal, and/or self-care) and signs of the illness must persist for six months (APA, 2013). In creating the DSM-5 diagnostic criteria for schizophrenia, the following three substantial changes were made to the DSM-IV criteria: (a) removal of schizophrenia subtypes, (b) requirement that one of the two present symptoms be delusions, hallucinations, or disorganized speech, and (c) definitional changes in course specifiers (e.g., removal of “single episode and episodic” (APA, 2000, p. 157), replaced with first episode and

multiple episode (APA, 2013, p. 100); and addition of current severity level rating). In most cross-cultural studies investigating differences in schizophrenia outcomes across sociocultural settings (i.e., developing and developed countries), the researchers define schizophrenia by the diagnostic criteria of the current era, and actually employ similar measures assessing presence of positive and negative symptoms. In fact, many authors of studies conducted in the developing world sought successfully to validate that the presentation of schizophrenia in developing countries was the same as European countries (e.g., Napo, Heinz, & Auckenthaler, 2012).

The DSM-5 reports a lifetime prevalence of 0.3%-0.7% for schizophrenia. However, this rate can vary cross-culturally, by race/ethnicity, and by geographic origin for immigrants and their children (APA, 2013) as well as by illness definition and geographic location (Castle & Morgan, 2008). The incidence of schizophrenia in the United States is 1.1% of adults, or 2.5 million people (WHO, as cited in Taylor, 2011); men have a higher incidence than women. However, the lifetime course of schizophrenia affects an equal number of men and women generally (Brown & Barlow, 2011). The critical need for MHPs to intervene during first-episode psychosis with both pharmacological and psychosocial interventions has been well established (Addington & Addington, 2008; Division of Psychologists in Public Service and American Psychological Association (APA) Task Force on Serious Mental Illness (SMI) and Severe Emotional Disturbance (SED), 2009), as delaying diagnosis and treatment may have serious consequences on the course and outcome of schizophrenia.

Etiological Theories of Schizophrenia

Biological/genetic. In spite of Downar and Kapur's (2008) conclusion that "the etiology and pathophysiology of schizophrenia remain incompletely understood" (p. 33), the biological model continues to be viewed as the primary etiological understanding of schizophrenia (Harland

et al., 2009). Accumulating evidence supports the role of genes and heritability in the development of schizophrenia (e.g., Schizophrenia Working Group of the Psychiatric Genomics Consortium, 2014), particularly psychotic symptoms (Karoutzou, Emrich, & Dietrich, 2008; Polanczyk et al., 2010; van Os, Hanssen, Bak, Bijl, & Vollebergh, 2003). Monozygotic twin studies have found that if one of the twins had schizophrenia, the other twin had a 48-53% risk of developing schizophrenia (Tsuang, Stone, & Faraone, 1999), while only a 10% risk was found for fraternal twins (Downar & Kapur, 2008, p. 27). Additionally, research has found the risk of developing schizophrenia to be higher for first-degree than second-degree relatives of individuals diagnosed with schizophrenia. Furthermore, family members of individuals diagnosed with schizophrenia have a greater risk of developing the disorder than those families without a diagnosed member in the general population (Lavretsky, 2008).

Unfortunately, the particular gene(s) underlying the vulnerability to develop schizophrenia have not been identified (Brown & Barlow, 2011; Downar & Kapur, 2008); moreover, replications of genetic linkage studies assessing differing genes have produced inconsistent results (Karoutzou et al., 2008). Professionals long believed that schizophrenia was the sole result of excess dopamine in the brain, known as the dopamine hypothesis (Haracz, 1982; Steele, Moore, Swan, Grant, & Keltner, 2012). However, evidence illustrating the impact of dopamine on symptoms of schizophrenia is contradictory, suggesting an unclear link between dopamine and schizophrenia (Haracz, 1982). Researchers are now considering how the combination and interaction of dopamine with other neurotransmitters may better explain the symptoms of schizophrenia (Brown & Barlow, 2011), as studies have found “a variety of neurochemical abnormalities, ranging from excessive to deficient concentrations of dopamine, serotonin, and glutamate, in studies comparing patients with schizophrenia and controls”

(Lavretsky, 2008, p. 7).

Biopsychosocial. Conceptualizing schizophrenia solely from a biological etiology may influence the narrow conclusion that only pharmacological and inpatient treatment is necessary. As such, the Division of Psychologists in Public Service and APA Task Force on SMI and SED (2009) recommend MHPs adopt a biopsychosocial perspective, which involves gaining “extensive knowledge of the biological, as well as psychological and social, aspects of SMI” (p. 18). Focusing on only one of the three factors that contribute to schizophrenia results in a limited and incomplete understanding of the disorder (Strauss & Carpenter, 1981).

Diathesis-stress. The diathesis-stress model accounts for environmental factors in the development, course, and outcome of schizophrenia, in addition to social and psychological factors. The fact that a monozygotic twin with schizophrenia also may not have a twin who develops schizophrenia (Brown & Barlow, 2011) provides support for the role of environmental and psychosocial factors in the development, course, and outcome of schizophrenia. In this model, environmental stress is thought to trigger an underlying biological vulnerability that results in the development of schizophrenia (Zubin & Spring, 1977). A common environmental factor that may positively or negatively influence the course of schizophrenia is the household, or family dynamic, in which the individual lives (Barrowclough & Lobban, 2008). For example, a well-researched environmental factor on the course of schizophrenia is expressed emotion among families. A high level of expressed emotion is characterized by “critical comments, hostility, and/or over involvement of family members with nominally more than 72 hours per week of face-to-face contact with the individual” (Castle & Morgan, 2008, p. 22). High levels of expressed emotion from family members are predictive of relapse but not implicated in the overall cause of schizophrenia, and therefore, are only influential on the course of illness (Shean,

2009), strongly correlating with a poor outcome (Castle & Morgan, 2008).

Walker and Diforio (1997) proposed a “neural diathesis-stress model” (p. 677) in which stressors may be biological, in addition to environmental and psychosocial, in the form of “prenatal/perinatal insults” (p. 678; e.g., “intrauterine infections” or “obstetric complications;” Downar & Kapur, 2008, p. 26), that interfere with a person’s homeostatic mechanisms. Environmental and social stressful life events may include, but are not limited to, wartime combat (Dohrenwend & Egri, 1981) “a personal or family history of migration...urban residency, minority ethnicity, childhood trauma, and social isolation” (Downar & Kapur, 2008, p. 26). In particular, within the diathesis-stress model, childhood trauma is viewed as a causal factor in the development of psychosis and schizophrenia, especially hallucinations (Larkin & Read, 2008; Whitfield, Dube, Felitti, & Anda, 2005).

Cognitive/neuropsychological. Those conceptualizing the etiology of schizophrenia from a cognitive/neuropsychological model focus on impairments in cognitive functioning (Fyfe, Williams, Mason, & Pickup, 2008; Kurachi 2003; Rossell, Batty, & Hughes, 2010), most often in areas of “attention, working memory, visual and verbal learning, psychomotor speed, and executive functions” (Savla, Moore, & Palmer, 2008, p. 92). For example, working memory deficits have been implicated in partially underlying disordered thought (Goldman-Rakic, 1994). Additionally, So, Garety, Peters, and Kapur (2010) demonstrated support for an association between delusion severity and belief rigidity, as well as a tendency to reach conclusions quickly without complete understandings. Abnormalities in perception are also hypothesized and described in the development of delusional thinking (Langdon & Coltheart, 2000; Rossell et al., 2010). Although studies have identified structural, brain abnormalities, it is not yet understood how such abnormalities underlie the manifestations of positive, negative, and cognitive

symptoms (Downar & Kapur, 2008).

Psychodynamic. The psychodynamic etiological model asserts that “infantile traumas and early rejection experiences” are the cause of schizophrenia (Lavretsky, 2008, p. 10) as well as “disturbances in ego function and object relations” (Vahia & Cohen, 2008, p. 84). For example, in psychoanalytic theory, a delusion is conceptualized as a defense mechanism against disturbing emotions from childhood and symptoms of traumatic or stressful life events (Bodei & Webb, 2005; Karon, 2001; Lester, 1975; Searles, 1965). The individual with schizophrenia is forced to make sense of these devastating events and associated meanings in everyday life (Bodei & Webb, 2005; Karon, 2001). Attempts at sense-making are abnormal and may manifest as delusions, as delusions are interpreted as “expressions of underlying intrapsychic conflicts or defects” (Heinrichs, 1988, p. 276).

Cross-cultural. Etiological theories of schizophrenia in other countries vary and incorporate other possible reasons for symptoms beyond the theories endorsed by the U.S; some of these are subjective rather than theoretical (Napo et al., 2012). For instance, Bhugra (2006) stated that the disease of schizophrenia, referring to its underlying pathology, becomes defined as an illness by the culture from which it emerges: “It is the culture which determines what illness is, how sick role is defined, and what help is sought” (p. 20). Furthermore, Bhugra stressed the importance of understanding the diagnosis within the individual’s cultural context and how the culture may exacerbate or alleviate the individual’s course of illness.

A Brief History and Evolution of Schizophrenia in the U.S.

Institutionalization to de-institutionalization. Long-term institutionalization was a common treatment for schizophrenia and other SMIs before the advent of psychiatric medication in the 1950s (Lavretsky, 2008; Strauss & Carpenter, 1981). Underlying prolonged

institutionalization was an attitude promoting devaluation and segregation of individuals with SMIs from society (Whitaker, 2002). Strauss and Carpenter described psychiatric hospitals as having “chronicity-inducing effects” (p. 65) on the course of schizophrenia for those individuals institutionalized with the diagnosis. By its very nature, extended institutionalization diminished motivation, coping skills, social skills, and general socialization. As the inpatient units were not often centrally located, families could not easily visit. Moreover, there were many rules and restrictions around visiting, and even letter writing, all of which promoted social isolation for the diagnosed individuals (Strauss & Carpenter, 1981).

Thought to be plagued by an unidentifiable brain disease (Lidz, 1973), and consequently viewed as incurable, psychiatric patients remained in insane asylums for many years, often for lifetimes. In addition to brain damage (Lidz, 1973), many of the treatments provided during institutionalization exacerbated existing symptoms and prolonged the illness, delaying recovery (Whitaker, 2002). These treatments included, but were not limited to, *prolonged barbiturate-induced sleep therapy* (Valenstein, 1986, as cited in Lavretsky, 2008), insulin-coma therapy, metrazol, electric shock therapy, frontal lobotomies (Lidz, 1973), and baths of surprise (Whitaker, 2002; White, 2013).

By 1954, the arrival of Thorazine largely initiated the de-institutionalization of individuals from insane asylums (Arbeitman, 2012; White, 2013). This antipsychotic—or neuroleptic—medication’s ability to stabilize and manage the psychotic symptoms, and strange behavioral characteristics of schizophrenia afforded psychiatric patients the opportunity to receive community mental health services and integrate into society (Arbeitman, 2012; Whitaker, 2002; White, 2013). Although antipsychotics did not ameliorate hallucinations or delusions, they reduced severity (Lavretsky, 2008), making symptoms more tolerable to the individuals

experiencing them, and likely to the communities in which they lived.

Unfortunately, the benefits expected to emerge from de-institutionalization of individuals with SMIs did not fully actualize. Patients were discharged and received insufficient community after-care, including a lack of functional support, such as training of occupational, social, and/or activities of daily living (ADL) skills (Lavretsky, 2008). Available community programs were severely underfunded, and did not coordinate their services (Armstrong, 1977, as cited in Anthony, 2000). The positive treatment outcomes achieved during institutionalization were further undermined by the poverty and stigma that accompanied de-institutionalization (Lavretsky, 2008). Finally, although deinstitutionalization brought with it shortened psychiatric hospitalization stays, the number of institutional admissions increased. This hospitalization phenomenon, known as the *revolving door*, demonstrated the inability of community-based treatment to prevent the re-hospitalization of those with SMIs (Felix, Herman, & Susser, 2008).

The role of medications in creating and maintaining mental illness. The arrival of antipsychotic medication was complicated and controversial as (a) antipsychotic medications, such as Thorazine, were effective in reducing symptoms, including mood issues, positive symptoms, and some negative symptoms (Lavretsky, 2008); and (b) neuroleptics also caused symptoms, including but not limited to drowsiness; blurred vision; dry mouth (Brown & Barlow, 2011); *extrapyramidal side effects* (EPS), including *acute dystonia*, *Parkinsonism*, *akathisia*, *tardive dyskinesia* (TD); *neuroleptic malignant syndrome* (NMS), diabetes (Castle & Morgan, 2008), weight gain; *orthostatic hypotension*, *the metabolic syndrome* (i.e., *hypertension*, *hyperlipidemia*, *obesity*, and *hyperglycemia*, and *hematological toxicity* (Dolder, 2008). Although second and third-generation antipsychotics have fewer neurological side effects than first-generation antipsychotics (Dolder, 2008), they come with their own side effect profiles,

some of which are life-threatening if not monitored, as with Clozaril (Kane & Marder, 2005).

Robert Whitaker, in his 2002 book, *Mad in America*, details the role of neuroleptics in both creating the symptoms originally conceptualized as schizophrenia by Kraepelin, and perpetuating the experience of the illness. Whitaker makes a powerful argument describing how neuroleptics actually produce the physical symptoms of schizophrenia, mainly Parkinsonism but also weight gain (Boyle, 1990). Such physical symptoms, thought to create the deteriorating course associated with schizophrenia, were actually later thought to be attributable to *encephalitis lethargica* (Sacks, 1973, as cited in Whitaker, 2002), an organic brain disorder. Because the patient population Kraepelin diagnosed to have schizophrenia was comprised of many individuals with *encephalitis lethargica* (Boyle, 1990), it appears that Kraepelin created criteria of a syndrome that was based off of a population with an actual medical illness, with a known and direct cause, unlike schizophrenia. Further support for Kraepelin's psychological diagnosis of a medical illness comes from a similar decline in the incidence of Kraepelin's schizophrenia with the 1920s decline in cases of *encephalitis lethargica* (Whitaker, 2002).

Whitaker described how, as a result, the physical symptoms of schizophrenia were eliminated from the diagnostic criteria, leaving only the pathological, psychological symptoms (i.e., hallucinations, delusions, bizarre thoughts). When neuroleptic medications were introduced, Whitaker argued, they brought with them the same physical symptoms of *encephalitis lethargica*, as both the neuroleptics and *encephalitis lethargica* interfered with the dopamine system. Ultimately, the fact that neuroleptic side effects were identical to the physical symptoms of Kraepelin's schizophrenia, but may actually have been *encephalitis lethargica*, led to confusion about cause and effect.

Whitaker (2002) described how neuroleptics may also delay recovery by requiring

extended periods of hospitalization and causing general deficits in physical, cognitive, and emotional functioning. Relapses are common among individuals who discontinue their antipsychotic medication (Lavretsky, 2008). Abrupt stops in medication often resulted in severe withdrawal symptoms and a “higher risk of relapsing than if they [diagnosed individuals] had never been exposed to the drugs” (Whitaker, 2002, p. 185). Additionally, 40% of first-episode diagnosed individuals relapsed while *on* neuroleptics during the first year (Whitaker, 2002). Serious consequences of long-term neuroleptic use included experiencing a chronic course of illness, engaging in violent and criminal behavior, becoming socially withdrawn, irreversible brain damage, and premature death (Whitaker, 2002).

The evolving role of diagnosis. Symptoms of Kraepelin’s dementia praecox historically influenced our understanding of schizophrenia and included the following:

hallucinations, usually of an auditory or tactile form; decreased attention to the outside world; lack of curiosity; disorders of thought...with unusual and partly comprehensible associations; changes of speech resulting from the thought disorder, such as incoherence; lack of insight and judgment; delusions; emotional blunting; negativism; and stereotypy. (Vahia & Cohen, 2008, p. 82-83)

Additionally, our current understandings of executive functioning deficits are similar to those Kraepelin described as characteristic of schizophrenia, including difficulties with attention and initiation (Zec, 1995).

In 1911, psychiatrist Eugen Bleuler from Switzerland replaced the label *dementia praecox* with *schizophrenia* to emphasize a psychological rather than neuropathological conceptualization of schizophrenia (Lavretsky, 2008). Despite having a better prognosis, Bleuler’s definition of schizophrenia continued to lack a restoration of premorbid functioning

(Vahia & Cohen, 2008). Bleuler separated symptoms into two categories: primary and secondary. Primary symptoms included “disturbances in association, thought disorder, changes in affectivity, a tendency to prefer fantasy to reality and to seclude oneself from reality, and autism” (Vahia & Cohen, 2008, p. 83). Secondary symptoms, thought to be psychological reactions to primary symptoms,” included “hallucinations, delusions, catatonic symptoms, and various behavioral abnormalities” (Vahia & Cohen, 2008, p. 83). Bleuler’s cognitive/neurological conceptualization and formalization of schizophrenia influenced a broader diagnostic definition of schizophrenia that encompassed several neuropsychiatric disorders in the U.S. from the early 20th century through the 1970s with the developments of DSM I & II (Lavretsky, 2008).

By 1957, Kurt Schneider re-conceptualized delusions and hallucinations as *first-rank symptoms*, describing them as “audible thoughts, voices arguing or discussing or commenting, thought control or thought broadcasting, ‘made’ acts and emotion, and delusional perceptions” (Downar & Kapur, 2008, p. 26). In particular, Schneider focused on the form of the symptoms, rather than the content, in diagnosing individuals with schizophrenia. Overall, Schneider’s first-rank symptom descriptions shaped our current diagnostic criteria, as they strongly influenced the development of DSM-III and ICD classifications.

Despite a few diagnostic reformulations, over-diagnosis of schizophrenia has been a particular concern for specific populations. For example, over-diagnosis of schizophrenia in African Americans has been a historical issue (Lawson, 2008). Additionally, research has found that “first-generation migrants and their offspring are at a higher risk of developing schizophrenia than native-born white inhabitants” (Castle & Morgan, 2008, p. 17). Finally, a diagnosis of schizophrenia in individuals from low, socioeconomic backgrounds is also more common, and among this population, the risk of developing schizophrenia is higher for

immigrants from developing countries than developed (Cantor-Graae & Selten, 2005). The unresolved issue is whether African Americans and the poor are receiving the schizophrenia diagnosis based on these diversity attributes in clinical practice, or whether they are actually at higher risk of developing schizophrenia *because* of these diversity attributes.

The evolution of stigma. Societal stigma towards individuals with schizophrenia, and SMI in general, was observed as least as far back to the late 1750s with the regular occurrences of public taunting and humiliation of psychiatric patients (Whitaker, 2002). Individuals diagnosed with schizophrenia have cited barriers to recovery, including MHPs' use of insensitive and debilitating language (e.g., chronic, incurable) to describe their illnesses to clients and their families (Friedman, Procci, & Fenn, 1980), discouragement of hope, emphasis on symptoms and medication, and "stigmatizing practices" (Tooth et al., 2003, p. S73). By engaging in such ways with diagnosed individuals and their families, MHPs may unintentionally perpetuate ever-present public stigma towards individuals with SMI (Corrigan, 2004). There are many instances where MHPs have told individuals with schizophrenia that they will never recover or regain previously lost abilities or skills, and discouraged individuals from pursuing various life goals (Frese & Davis, 1997; Hornstein, 2009; Paquette & Navarro, 2005). In addition, diagnosed individuals have also been told they will remain on medication for the remainder of their lives (Fisher, 2003; Whitaker, 2002). In one qualitative investigation of the elements involved in the recovery process from schizophrenia, "aspects of medication" and "impact of health professionals" were among the most negative factors of participants' recovery experiences (Tooth et al., 2003, p. S72).

Research examining attitudes towards schizophrenia has yielded varying and inconsistent reports of negativity among different MHPs, healthcare professionals, and the general population

(Hori, Richards, Kawamoto, & Kunugi, 2011; Jorm, Korten, Jacomb, Christensen, & Henderson, 1999). For instance, Jorm et al. (1999) found psychiatrists to hold more negative attitudes towards schizophrenia than the general population, while Hori et al. found the opposite. Additionally, Woodside et al., (1994) found no differences in hopefulness between MHPs and the general population regarding recovery from schizophrenia.

Perceived chronicity of schizophrenia based on homogenous clinical experiences of continual impairment among individuals with the diagnosis (Harding, Zubin, et. al., 1987), as well as a lack of drastic improvements over an extended period of time, may both contribute to negative attitudes toward their recoveries (Harding et al., 1992; Jorm et al., 1999). Negative attitudes about treatment outcomes may also be maintained by a lack of opportunity to see clients recover in some capacity due to, for example, psychotherapy termination or client drop out (Warner, 2009). Additionally, some MHPs have also felt their own inaccurate understandings of schizophrenia, and fear of severe pathology, have impeded client improvement (Torgalsbøen, 1999). These recovery barriers likely underlie the negative attitudes towards schizophrenia that further encourage practitioner distance from those diagnosed with the illness (Hori et al., 2011).

Unfortunately, after years in the mental health system, individuals diagnosed with schizophrenia also develop negative attitudes towards themselves, and a diminished hope for recovery (Hornstein, 2009). Perceived and experienced social stigma may be transformed and internalized into self-stigma (Davidson, Borg, Marin, Topor, Mezzina, & Sells, 2005; President's New Freedom Commission on Mental Health, 2003) and further hinder recovery (Perlick et al., 2001). The stigma of schizophrenia itself prevents even those recovered individuals from sharing their experiences and stories with others, including their MHPs (Fisher, 2003; Hornstein, 2009). In essence, this lack of self-disclosure may underestimate the total number of individuals who

regard themselves as recovered from schizophrenia, irrespective of the recovery definition. In sum, poor MHP attitudes towards recovery can, and do, negatively affect the client's potential for recovery (Paquette & Navarro, 2005; Tooth et al., 2003). These negative perceptions and attitudes biased against recovery in schizophrenia may prevent promotion of an integration of recovery concepts, and sustain a delimiting self-fulfilling prophecy.

Outcome-Based Recovery Definitions

Outcome-based definitions of recovery include symptom amelioration, reduction, and remission. Outcome-based definitions of recovery emerged out of a historical tradition emphasizing the importance of measuring outcomes in treatment research (Bellack, 2006), and the medical model. Up until the 1970s, before the initiation of the consumer recovery movements (Anthony, 1993; Frese & Davis, 1997), many MHPs ascribed to a medical model framework of recovery, where psychiatric disorders were conceptualized as medical illnesses, and symptom amelioration and a return to pre-morbid functioning constituted recovery (Corrigan & Ralph, 2005; Thornhill et al., 2004). As such, medication use is primary treatment from a medical model framework, as the biological etiological theory of schizophrenia underlies the medical model (Munetz & Frese, 2001). Generally, the medical model is perceived to heavily focus on an individual's illness, deficits, and limitations, rather than strengths, improvement in health, and an ability to flourish. Hope appears absent (Munetz & Frese, 2001).

Possible outcomes of schizophrenia, from a medical-model perspective, include symptom amelioration, reduction, management, and remission. Symptom amelioration is thought to involve an inherent ending to the illness, a return to normal functioning, achievement of specified life goals, and overall improved quality of life (Corrigan & Ralph, 2005). A major drawback of the symptom amelioration conception of outcome is the ambiguity surrounding the

number of achieved outcomes that must be attained for someone to be labeled as 'recovered' (Corrigan & Ralph, 2005).

Symptom reduction and subsequent management are based on a *maintenance model* assumption that individuals do not improve after reaching a particular point in their treatment (Paquette & Navarro, 2005; Weiden, 2005). From this recovery frame, individuals with schizophrenia are often encouraged by professionals to accept the chronicity of their illness and maintain a stance of little to no hope for complete recovery (Frese & Davis, 1997; Warner, 2009). The connotations of this type of mental illness acceptance are much more negative and potentially stigmatizing than that of acceptance in the process model of recovery. However, importantly noted, the medical model does support some degree of functionality, as one has to experience a loss in one or more areas of psychosocial functioning to receive a diagnosis of schizophrenia (APA, 2013). Moreover, a return to pre-morbid functioning is emphasized.

Schrank and Slade (2007) define *remission*, in the context of psychiatry, as "an improvement in symptoms and other deficits to a degree that they would be considered within a normal range" (p. 321). However, it seems that the threshold of what counts as reduction in symptoms varies with the outcome criteria and measures used in a given study. Within the medical model, remission appears to fall somewhere in between definitions of symptom reduction and amelioration. Furthermore, DSM-5 is consistent with the outcome-based definition of recovery, including part and full remission of symptoms of schizophrenia (APA, 2013). It follows that only a small number of individuals recover according to DSM-5 criteria. As with earlier editions of the DSM, recovery is defined by outcome, excluding process and consumer perspectives.

Outcome-based understandings of recovery are linguistically identifiable. For example,

recovery 'from' schizophrenia connotes that one has recovered from the experience of symptoms, an outcome description (Davidson & Roe, 2007). Recovery may also signify that one has experienced a recovery 'of' previous lost functions or abilities, (Davidson, Lawless et al., 2005; Peer et al., 2007), such as social skills or *vocational functioning* (Kane, 2003).

This recognition of variations in improvement, and ongoing challenges, begins to bridge the gap between outcome and process definitions of recovery. The fact that treatment of schizophrenia with medication has been beneficial for many diagnosed individuals (Corrigan & Ralph, 2005) emphasizes the importance of synthesizing both understandings of recovery. Additionally, the President's New Freedom Commission on Mental Health (2003) acknowledged that recovery may constitute different meanings for different individuals, including both the reduction or remission of symptoms and/or "living a fulfilling and productive life despite a disability" (p. 5). This recovery understanding more accurately reflects the variability with which consumers define their personal recoveries (Thornhill et al., 2004).

Process-Based Recovery Definitions

The process-based definition of recovery, as understood and discussed in the current professional literature, largely emerged and advanced from the consumer advocacy movement (Tomes, 2006). According to Chamberlin (2005):

The main concerns of user/survivor/consumer organizations include limitations on involuntary commitment (and its eventual elimination), improvement of institutional conditions, the development and support of user-controlled alternative services, combating discrimination, and the promotion of services and supports that promote recovery. (p. 11)

For over two decades, a subset of individuals diagnosed with psychiatric illnesses have created

and promoted their own definitions of recovery. Individuals of the consumer/survivor movement subscribe to the notion that recovery from mental illness does not have to signify a reduction in or remission of symptoms or a return to pre-morbid functioning (Davidson, 2003). An individual can be in recovery while still experiencing some of the symptoms of schizophrenia (Davidson et al., 2005; Davidson & Roe, 2007; Silverstein & Bellack, 2008). Recovery *in*, versus recovery *from* schizophrenia (Davidson & Roe, 2007), encompasses a strength-based approach to recovery, where individuals focus on strengths instead of perceived deficits (Schrack & Slade, 2007). Recovery, then, for individuals with schizophrenia does not necessarily mean getting rid of the illness but rather regaining the ability to be the “expert in their own lives” (Ross Ellenhorn, personal communication, August 4, 2016), which may include achieving personal goals and desires and attaining a sense of purpose in life. As such, it is important to distinguish between the conceptualization of recovery in mental health treatment and the actual use of the term with diagnosed individuals, as some may not want to label their pursuits of their desires as recovery. In contrast to the outcome model of recovery, there is also growing outcome research supporting continued improvement in life and symptom functioning without an inherent end point (Weiden, 2005).

Because consumer/survivors do not equate recovery with an end result or cure, and alternately view recovery as a lifetime, individualized process, the actual process of recovery is thought to transcend definitional criteria, as individuals' recovery paths will differ in time, course, and content (Davidson, 2003). As such, recovery is often conceptualized as “an attitude, a way of life, a feeling, a vision, or an experience” (Davidson, 2003, p. 44). The consumer/survivor recovery concept concerns “learning how to live with and manage or compensate for an ongoing condition, while being engaged in the process of living one's life as

fully as possible within or beyond the limitations imposed by that condition” (Davidson et al., 2005, p. 180). Recovery involves gaining a sense of agency in life (Davidson & Roe, 2007), empowerment (Warner, 2009), and psychological well-being, where individuals derive meaning and satisfaction from life (Anthony, 1993; Corrigan & Ralph, 2005). Additionally, recovery emphasizes choice in terms of rights, including but not limited to the right to treatment, treatment refusal, and privacy (Munetz & Frese, 2001). Most importantly, recovery entails no longer feeling a sense of societal rejection, social isolation, and social stigma (Anthony, 1993). According to the consumer/survivor view of recovery, individuals with SMI should be actively involved in all aspects of their psychotherapy treatments (Spaulding & Nolting, 2006).

From repeated, qualitative research of personal accounts, Davidson (2003) has identified the following several common elements of the recovery process in schizophrenia: (a) *overcoming stigma*, (b) *renewing a sense of hope and commitment*, (c) *resuming control over and responsibility for one's life*, (d) *exercising one's citizenship*, (e) *managing symptoms*, (f) *being supported by others*, and (g) *being involved in meaningful activities and expanded social roles*. The concept of hope, in particular, plays a primary role in the process of recovery in schizophrenia (Corrigan & Ralph, 2005) and in SMI in general (Anthony, 1993; Spaulding & Nolting, 2006), as it encompasses a hope for the future (Davidson, 2003), in addition to a renewed sense of hope after diagnosis. Other elements of recovery from SMI in general include some level of illness acceptance and discovering a transformed sense of self (Davidson, 2003). In contrast to the medical model of recovery, acceptance involves accepting that one's life can continue positively in the context of the illness (Davidson & Roe, 2007). These perceptions of recovery transcend conventional views as they depict recovery as a process, (Anthony, 1993; Frese & Davis, 1997), rather than an outcome.

Bridging the Gap

Bridging the gap between recovery models may occur when MHPs are more willing to collaborate, and consumers incorporate the benefits of the medical model in their process of healing. For instance, some MHPs do assert that symptomatic remission may be an element of the consumer notion of recovery (Leucht & Lasser, 2006); this is one example of how the gap between outcome and process models of recovery might be bridged. In a bolder way, *recovery dialogues* are bridging this gap in various places across the U.S. (Blanch, Fischer, Tucker, Walsh, & Chassman, 1993, as cited in Jacobson & Curtis, 2006). Simply, recovery dialogues involve MHPs and mental health system users having open-minded and collaborative discussions about recovery. In a similar vein, the Substance Abuse and Mental Health Services Administration's (SAMHSA) description of mental health recovery was created by a focus group of consumers, their families, and a variety of professionals related to the mental health field at the National Mental Health Consensus (SAMHSA, 2004). The document produced from the focus group incorporates process-definitions of recovery, and the consumer/survivor perspective.

According to SAMHSA (2004), mental health recovery is comprised of the following 10 key concepts: (a) *self-direction*, (b) *individualized and person-centered*, (c) *empowerment*, *holistic*, *non-linear*, *strengths-based*, *peer support*, *respect*, *responsibility*, and *hope*. SAMHSA provided a brief and general description of recovery from mental health problems as a process, understanding the process as a "journey of healing and transformation enabling a person with a mental health problem to live a meaningful life in a community of his or her choice while striving to achieve his or her full potential" (p. 1). All of the key elements are thought to be a part of, and integral to, the process of recovery. The SAMHSA (2004) conceptualization of recovery

seems to naturally allow for the integration and incorporation of other definitions of recovery, given its emphasis on multiple pathways to recovery and consumer-selected goals of recovery.

Incorporating social context as a means of bridging. Both outcome and process conceptualizations of recovery are absent of clear developmental and systemic influences in the construction and definition of recovery. Notably, both the medical/outcome model and the consumer/process model focus primarily on the diagnosed individual. For example, in the process conceptualization of recovery, the diagnosed individual's meaning of and plan for recovery are privileged. As a result, the actual process of recovery is—at least theoretically—highly individualistic, as the individual is thought to be responsible for directing his or her own recovery. This conceptualization may run into conflict with family approaches to the recovery. For example, family strategies often focus on resolving disputes about the progress and recovery goals of the individual; family members may not agree that the individual's ideas and attitudes of recovery should be prioritized above those ideas and goals of the family (Glynn, Cohen, Dixon, & Niv, 2006).

Given the individualistic underpinnings of the recovery orientations, developmental and systemic factors affecting the formation of an individual's recovery path may be insufficiently considered. It remains a fact that more than 60% of individuals with a first-episode of a serious mental illness return to reside with relatives as a result of the episode (Barrowclough & Lobban, 2008), and their sustained positive engagement may be integral to recovery. Thus, a question remains as to the role and influence of family and community in, for example, the adolescent/young adult's meaning and conceptualization of his or her recovery path from schizophrenia, since the individual is pursuing recovery in a social context.

Furthermore, although familial and social support can mediate the negative effects of

social stressors and improve social function and quality of life for individuals diagnosed with schizophrenia (Gumley & Clark, 2012), the exact mechanism of how familial and social support accomplishes this is still unclear, as well as exactly how friends and family play a role in diagnosed individuals' recoveries from schizophrenia. With regard to the role of family and social support in recovery, the following questions remain: Are family and social support most helpful when they support and promote the individual's conception of his or her recovery? Can the family and friends' views of recovery and progress still be supportive of the diagnosed individual's path to recovery, even if those views differ from the individual's? The constructionist framework allows for an explicit consideration of the social contexts of both outcome and process recovery orientations—including the roles of family, systems, and developmental stage, on individual recovery paths—to yield a truly integrated model of recovery.

Facilitators of Recovery: A Summary of Interventions for Schizophrenia

Evidence-based pharmacological interventions. The Schizophrenia Patient Outcomes Research Team (PORT) provides a current summary of evidence-based pharmacological interventions for the treatment of schizophrenia (Buchanan et al., 2010). Those recommended treatments include, but are not limited to, *acute antipsychotic treatment*, with the exception of clozapine (Buchanan et al., 2010); *antipsychotic choice for first-episode schizophrenia*, with the exceptions of clozapine and olanzapine (Buchanan et al., 2010); and *maintenance antipsychotic medication treatment* (Buchanan et al., 2010). Additionally, use of Clozaril is recommended for the treatment of “positive symptoms in treatment-resistant people with schizophrenia” (Buchanan et al., 2010, p. 79). Other pharmacological interventions for which there is an insufficient evidence base but are potentially efficacious for the treatment of schizophrenia and associated symptoms of anxiety, depression, hostility and/or poor cognition; and comorbid

diagnoses, include but are not limited to *antipsychotic polypharmacy*, *anticonvulsants*, and *lithium for treatment-resistant positive symptoms* (Buchanan et al., 2010). Finally, electroconvulsive therapy (ECT; Buchanan et al., 2010; McClintock, Ranginwala, & Husain, 2008), a long-time controversial treatment (Carney & Geddes, 2003), requires more research of efficacy.

Individuals diagnosed with schizophrenia receiving pharmacological treatment are often prescribed more than one antipsychotic medication, even though monotherapy remains the recommended best practice (Wolff-Menzler, Hasan, Malchow, Falkai, & Wobrock, 2010). Thus, future research using randomized clinical trials (RCTs) should investigate the efficacy of combination pharmacotherapy, as the current research in this area has yielded mixed results (Wolf-Menzler et al., 2010). Additionally, there is growing support for the efficacy of medications targeting glutamate receptors that may stand as alternatives to antipsychotics (Steele et al., 2012). Walker, Kestler, Bollini, and Hochman (2004) note how medication is typically the “first and the *only* treatment received by many patients” with schizophrenia (p. 419). In contrast, a combination of pharmacological and psychosocial treatment is considered the standard, best practice treatment for schizophrenia (Lavretsky, 2008).

Evidence-based psychosocial interventions. The Schizophrenia PORT also provides a current summary of eight evidence-based psychosocial interventions for the treatment of schizophrenia (Dixon et al., 2010). Those treatments include (a) cognitive-behavioral therapy (CBT; Dickerson, 2004; Grech, 2002; Rector & Beck, 2001), (b) family psychoeducation (FPE) therapy (Lucksted, McFarlane, Downing, Dixon, & Adams, 2012), (c) supported employment (SE), (d) social skills training, (e) assertive community treatment (ACT), (f) token economy (Shean, 2009), (g) *psychosocial interventions* for comorbid alcohol and/or substance use

disorders, and (h) weight management (Dixon et al., 2010). The PORT emphasizes that all psychosocial interventions are conjunctive with pharmacological treatment (Dixon et al., 2010). Although not as strong as that of CBT, there is also an evidence base for personal, compliance, and supportive therapies (Dickerson & Lehman, 2011). Finally, there is solid empirical support for the use of individual, psychodynamic psychotherapy in the treatment of schizophrenia (Gottdiener, 2006), as well as family therapy (Asmal et al., 2011).

Other psychosocial interventions for which there is an insufficient evidence base, but growing appeal, include cognitive remediation, peer supported and delivered services (Dixon et al., 2010), types of narrative therapies, mindfulness therapy, and *meta-cognitive training* (Dickerson & Lehman, 2011). Finally, interventions requiring more research of efficacy include cognitive-behavioral group therapy (CBGT; Lawrence, Bradshaw, & Mairs, 2006), *stress management training* (Walker et al., 2004), and, notably, the compelling and novel *Soteria paradigm* for individuals diagnosed with schizophrenia spectrum disorders (Calton, Ferriter, Huband, & Spandler, 2008, p. 181).

Briefly, the Soteria paradigm was developed by Loren Mosher and associates in the U.S.; the treatment approach is comprised of the following four central aspects: (1) “the provision of a small, community-based therapeutic milieu with significant lay person staffing;” (2) “preservation of personal power, social networks, and communal responsibilities; (3) “a ‘phenomenological’ relational style which aims to give meaning to the person’s subjective experience of psychosis by developing an understanding of it by ‘being with’ and ‘doing with’ the clients;” and (4) “no or low dose antipsychotic medication (with all psychotropic medications being taken from a position of choice and without coercion)” (Calton et al., 2008, p. 181). There are Soteria houses located in Vermont, California, and Alaska (Mackler, 2012). Based on a

systematic literature review of controlled studies comparing the Soteria paradigm to pharmacological treatment, the Soteria paradigm was found to be as efficacious as pharmacological treatment for individuals with first and second-episode schizophrenia spectrum disorders (Calton et al., 2008). Although no significant differences in efficacy were found, researchers emphasized the appeal of the Soteria paradigm over pharmacological treatment given the no to low use of medication in yielding the same results as medication alone. Additionally, positive cross-cultural treatment outcomes of Soteria homes were high in Switzerland, Sweden, and Finland (Whitaker, 2002).

Newer early interventions for first episode psychosis (FEP), known as Coordinated Specialty Care (CSC) programs, have been recently ushered in through the National Institute of Mental Health study known as Recovery After Initial Schizophrenia Episode (RAISE; Heinssen, Goldstein, & Azrin, 2014; Kane et al., 2015; Marino et al., 2015). CSC treatments, such as NAVIGATE, are comprehensive interventions that prioritize person-centered care, collaboration, and shared decision-making at the forefront of behavioral health care. NAVIGATE, for example, aims to help diagnosed individuals literally “navigate the road to recovery from an episode of psychosis” (Penn, Meyer, & Gottlieb, 2014, p. 5). The intervention is facilitated by a team of MHPs helping the individuals to accomplish aims in multiple facets of life (e.g., home, occupational, social) through the use of four core evidence-based practices (EBPs), including personalized medication management, family psychoeducation, Individual Resiliency Training (IRT), and supported employment and education (Insel, 2016).

Another approach to recovery resides under the broad umbrella of self-help activities. The central goal of the self-help model/group is to help individuals with SMIs achieve self-worth (Frese, 2008). For example, the *Hearing Voices Network* (HVN) is a type of psychiatric survivor

group within the self-help model of recovery for schizophrenia. HVN is characterized by acceptance and curiosity of the hearing voices experience, thus promoting consideration of the roles of the voices. These groups encourage the individuals themselves to consider alternative ways of coping and living (Hornstein, 2009). Other self-help groups include *Schizophrenics Anonymous* (SA; Frese, 2008) and NAMI.

Cross-cultural interventions. One of the main differences between the U.S. and other countries, particular developing, and more collectivistic societies, is the degree of family presence and involvement during the treatment. For example, in a study in Mali, West Africa, Napo et al. (2012) found that the company of a family member during hospitalization of an individual diagnosed with schizophrenia reduced aggression and stigma, increased the client's adherence during treatment, and helped the reintegration process of the patient back into the family (Napo et al., 2012). Familial and social contact was promoted throughout the entire therapeutic process by mandatorily admitting individuals diagnosed with schizophrenia, accompanied by a family member, to residential homes located in *psychiatric villages* (Napo et al., 2012), all of which are located in a hospital setting. At the residences, the patient's family member jointly participates with the patient throughout treatment, and continues to participate in activities already carried out in the home, such as cooking and cleaning. All clinical meetings with MHPs are held with both patients and their families (Napo et al., 2012).

The family member who accompanies the patient has other important healing responsibilities, such as bridging the gap of understandings of the illness between the patient and the rest of the family who were not present during treatment (Napo et al., 2012). In this study, researchers observed that patients and MHPs preferred a comprehensive treatment of psychotherapy, medication, *and* traditional remedies, such as theatre. Therapeutic theatre was

also found to be a useful treatment approach in reducing stigma of the illness among family members (Napo et al., 2012). Napo et al. highlighted the importance of guiding treatment of patients with an integrated model of both traditional and local etiological models of the patient's symptoms, emphasizing the need for a culturally sensitive diagnostic process that involves the family. This intervention model is quite consistent with constructionism: it acknowledges both patient and family have socially constructed ideas of what the patient is experiencing, and supports a shared understanding of, and investment in, recovery. It is unclear, however, the degree to which diagnosed individuals' illness understandings and treatment preferences differ from that of their families in other cultures at the outset of treatment, compared to such instances in the U.S. Therefore, it is important to understand how individuals in recovery from schizophrenia may be still fully supported in the context of opposing views of illness nature and necessary treatment goals by the immediate support system, regardless of culture.

The role of culture in treatment appears to be significant across the globe. For example, Lefley (2012) reviewed the literature on the cross-cultural use of family psychoeducation (FPE) for treating individuals with schizophrenia, and noted the benefits of making cultural adaptations. With the use of FPE, for instance, individuals with schizophrenia in China demonstrated a higher rate of recovery than controls. Recovery outcome criteria were defined as a "lower rate of exacerbation of symptoms and a reduction in annual relapse rates and annual times institutionalized" (Zhang, He, Gittelman, Wong, & Yan, 1998, p. S345).

In western Lapland of Finland, the *Open Dialogue* (OD) approach (Seikkula & Olson, 2003) has demonstrated effectiveness for the treatment of first-episode psychosis, including acute psychosis (Aaltonen, Seikkula, & Lehtinen, 2011), as well as schizophrenia (Seikkula et al., 2003). OD was developed in the context of the "Need-Adapted" approach in 1980s Finland for

SMI, the latter of which focused on immediate early intervention and flexible, client-centered treatment planning (Seikkula et al., 2003). In the OD approach, treatment is provided to the diagnosed individual in the context of his or her support system; the entire support system engages in “dialogical” communication and group meetings of the patient, providers, and support network (Seikkula et al., 2003, p. 164). Mobile crisis intervention teams are also utilized. The following are the seven, core principles underpinning the OD treatment approach: (a) *the provision of immediate help*, (b) *a social network perspective*, (c) *flexibility and mobility*, (d) *responsibility*, (e) *tolerance of uncertainty*, and (f) *dialogism* (Seikkula et al., 2003). Notably, OD programs are located in Denmark, Norway, Sweden, and Germany; and are also now being implemented in parts of the U.S (Ross Ellenhorn, personal communication, August 4, 2016).

One final approach worth noting is called the Runaway-house. In 1996, the Runaway-house was developed in Berlin, Germany, as part of the anti-psychiatry movement (Hölling, 1999). Diagnostic labels are not used or endorsed (Anonymous, 2013), as residents of the house are often against psychiatric medications and diagnoses (Hölling, 1999). The Runaway-house promotes mutual understanding, respect, and possibilities of the future (Anonymous, 2013), providing a space for psychiatric survivors to talk about their illness experiences, and explore their capacities of recovery, without the interference of medical and societal views of mental illness that could impede recovery (Hölling, 1999). Psychiatric survivors comprise at least 50% of the staff, and the residences themselves house about 13 people (Anonymous, 2013; Hölling, 1999). The focus of the stay, which can last up to six months, is on living everyday life through completing and maintaining household responsibilities (Hölling, 1999). With no therapeutic basis, the Runaway-house aims to provide support in any way residents' need, even including staff asking residents to articulate, for example “What helps you, if you get crazy?” (Hölling,

1999, p. 281).

Training Models for Mental Health Professionals Treating Serious Mental Illness

Education and training in SMI primarily takes place in professional psychology programs; it may be included in frequently offered courses pertaining to “psychopathology; diagnosis and assessment; general and specialized intervention theory and methods; quantitative methods and research design; cultural diversity, ethics, and professional issues; and psychopharmacology” (Division of Psychologists in Public Service, & APA Task Force on SMI and SED, 2009, p. 15). However, there is a dearth of research on the quantity and quality of SMI-training and education for clinical psychology doctoral trainees (e.g., Millet & Schwebel, 1994; Reddy, Spaulding, Jansen, Menditto, & Pickett, 2010), and “the comprehensive body of knowledge required to work effectively with those who have SMI is rarely available in professional psychology training programs” (Division of Psychologists in Public Service, & APA Task Force on SMI and SED, 2009, p. 15). The clinical training and education in SMI of MHPs is a necessary, beginning foundation to help those diagnosed to begin recovery (Reddy et al., 2010), making education and training all the more imperative. Additionally, with new roles being created for psychologists by the psychiatric rehabilitation and recovery movements, increased education and training in SMI is needed (Reddy et al., 2010).

Reddy et al. (2010) surveyed APA-accredited “Council of University Directors of Clinical Psychology (CUDCP) Clinical Psychology doctoral programs” about the degree to which psychology trainees were receiving comprehensive education and training in the elements of the recovery movement and recovery-oriented treatment for SMI, including relevant EBPs and related assessments and interventions. Although there has been an increase in faculty with special interests in SMI since the early 1990s, as well as SMI-related practica training and

research projects, results found the number of graduates choosing SMI-related careers was insufficient to meet the need of the SMI population (Reddy et al., 2010). Since availability of training and education is not the primary issue, but rather student interest, professional psychology training programs are advised to enthuse and educate psychology trainees about the critical importance of, and need for, working with individuals diagnosed with SMI, and avoid transmission of discouragement and stigmatizing attitudes about recovery for this population (Roe, Yanos, & Lysaker, 2006).

Reddy et al. (2010) also found that, in clinical psychology doctoral programs, coursework on pharmacological treatment was more common than psychosocial treatment for SMI. Thus, training programs are more frequently educating and training from a medical, rather than a process model of recovery, inherently limiting education about the multiple pathways to recovery. Moreover, Reddy and colleagues noted that training in the consumer perspective of recovery from SMI was a weakness of training programs; they recommended increased course exposure to the overall concept of recovery from SMI, including the consumer perspective (Reddy et al.). The development of an integrated graduate course curriculum for doctoral students about recovery in schizophrenia would begin to satisfy this training gap, as promotion of psychiatric rehabilitation and recovery from SMI relies on “the ability of the higher education system to conform to new demands” (Reddy et al., 2010, p. 261).

Qualitative Research Exploring the Process of Recovery in Serious Mental Illness

An important caveat to a discussion of recovery definitions is that all these definitions have been created by consensus among different groups, and not by empirical research (Bellack, 2006). This makes it difficult to advocate for changes in mental health care policy, when we lack a common language for definitions guiding treatment. In any case, few explorations have

qualitatively studied the recovery process in schizophrenia alone, typically grouping it with other SMIs. There are a few, however. For example, laying the groundwork for future research, Spaniol et al. (2002) conducted a longitudinal, qualitative analysis of the process of recovery by interviewing individuals, diagnosed with schizophrenia or schizoaffective disorder, about their life experiences every four to eight months during the course of four years. Interview data were qualitatively analyzed for recovery-related themes, patterns, and concepts. Spaniol and colleagues concluded that the recovery process (a) occurs in phases, where participants were initially overcome by schizophrenia, experienced difficulty coping, accepted and attempted to manage the illness, and finally transcended the illness, appraising it as a small part of life; (b) has different tasks, including formulating an etiology of the illness to better understand one's experience, exerting agency over the illness through coping and/or treatment, participating in and deriving success from meaningful and satisfying roles; (c) is facilitated by a network of supportive others, pharmacological treatment of acute symptoms, and fulfillment of basic needs; and (d) may be characterized by substance abuse and diversity factors of age of illness onset, poverty, and race (Spaniol et al., 2002).

Tooth et al. (2003) also interviewed individuals, identifying as in recovery from schizophrenia, about elements they endorsed as critical to the recovery process. Results of a thematic analysis yielded 111 elements; the most frequently identified elements included self-determination to recover, illness management strategies, and the self-realization that one requires help (Tooth et al., 2003). Additionally, Davidson's (2003) qualitative analyses of recovery experiences also found both facilitators of, and challenges, to recovery. Facilitators included acceptance from others, actively participating with others and one's environment, and experiencing pleasure and fulfillment. Challenges included stigmatization, rejection, failed

mastery experiences, particularly in completing daily tasks of life, and “withdrawal, isolation, and absorption in idiosyncratic ways of making sense of one’s illness-related experiences” (Davidson, 2003, p. 210).

Other research has focused on the processes and stages of recovery from SMI in general. For example, Ridgway (2001) investigated the process of recovery from chronic mental illness by qualitatively analyzing first person written narratives of recovery for common themes, using the constant comparative method. Results concluded the recovery process to frequently shift, from a phase of stagnation and disbelief of the possibility of recovery, to one of acknowledgement of illness suffering, and determination to achieve recovery and meaning with the help of supportive others (Ridgway, 2001). First person accounts shared common themes of recovery, including, but not limited to, the experience of “hope after despair,” overcoming initial denial with “understanding and acceptance,” and “moving from withdrawal to engagement and active participation in life” (Ridgway, 2001, p. 337). Additionally, Davidson et al. (2005) conducted a cross-cultural, qualitative study of the recovery processes in SMI; notably, nine of 12 participants in this study were diagnosed with schizophrenia. Common themes of recovery included, but were not limited to the following: “...the person’s determination to get better, establishing a degree of self-control, and struggling to achieve a normal life; the need for material resources and a sense of home, and the importance of going out and engaging in normal activities” (Davidson et al., 2005, p. 183).

Based on the existing scholarly literature, some attempts have been made to construct theoretically integrated models of recovery and stages of the recovery process. For example, Davidson and Roe (2007) discuss and describe how outcome and process models of recovery can co-exist in terms of recovery from SMI in general. Additionally, Schrank and Slade (2007)

proposed a conceptual framework of recovery from SMI, including stages of the process of recovery. However, this model does not exactly reflect an integration but rather proposes a framework of consumer-oriented views of recovery, as applied to SMI in general.

Although the process of recovery in schizophrenia has largely gone un-researched (Anthony, 2000), Anthony (1993) identified the following seven central elements of the recovery process based on the writings of mental health consumers: (a) professional help is not obligatory for recovery to occur; (b) recovery occurs in the context of present, supportive others, who have faith in the diagnosed individual; (c) recovery is not dependent on the diagnosed individual's etiological model of the illness but "understanding that there is hope for the future;" (d) recovery may occur and continue in the context of symptom relapse, (e) recovery is an individualized process with "no one path to recovery, nor one outcome," (f) recovery is marked by multiple options from which the individual may choose in constructing his or her recovery path, (g) "recovering from the consequences of the illness (e.g., 'discrimination, poverty, segregation, stigma, and iatrogenic effects of treatment') is sometimes more difficult than recovering from the illness itself," and (h) "recovery from mental illness does not mean that one was not really 'mentally ill'" (Anthony, 1993, p. 18-19). An additional element of recovery, common across different perspectives, includes the individual's ability to "take personal responsibility for his or her own recovery, often in collaboration with friends, family, supporters, and professionals" (Jacobson & Curtis, 2006, p. 361).

Summary: A Call to Research

The study aimed to generate an integrated recovery model of schizophrenia, as this population is viewed as one of the most vulnerable and resistant to recovery (Davidson, 2003). This research sought to answer the call for more qualitative research of the recovery process in

schizophrenia, to aid in developing a comprehensive model of recovery (e.g., Spaniol et al., 2002). This study also endeavored to contribute to a growing conversation of how recovery should be defined, and where recovery should be situated in professional training and practice (Roe et al., 2006). To this end, there is a critical need for the mental health field to focus on first person experiences of schizophrenia (Davidson et al., 2005; Tooth et al., 2003). One of my roles as a researcher includes “piecing together the common threads that may be found in individual stories” of recovery from schizophrenia (Reddy et al., 2010, p. 257). Systematically analyzing mental health consumer writings in the form of first person accounts for thematic elements that capture the process of recovery validates Anthony’s (1993) assumptive framework about the recovery process; resulting in a more enriched, detailed understanding of the process of recovery, including stages, for schizophrenia in particular; and most importantly, provides qualitative research support for the process of recovery.

Methodology

The purpose of this research was to construct a theoretically-informed, integrated model of recovery perspectives to (a) better understand the complexity of the path to, and definition of, recovery in schizophrenia, and (b) provide clinical psychology trainees with consumer-informed recommendations for working with individuals diagnosed with schizophrenia. My research questions included:

1. How do individuals with schizophrenia define and describe the process and facilitators of recovery?
2. In what ways do the recovery processes of individuals with schizophrenia mirror existing (e.g., medical, consumer/survivor) views of recovery? In what ways are they different?

3. What would an integrated model of the recovery process from schizophrenia look like were it to include: (a) best practices offered by each of the existing models of recovery, and (b) emergent views of diagnosed individuals?
4. How can a theoretically, integrated recovery model be incorporated into graduate-level clinical training?
5. How could an integrated recovery model be used in practice by MHPs?

This section describes the study's research methodology, and addresses the following areas: (a) rationale for research approach, (b) description of the research sample, (c) overview of information collected, (d) overview of research design, (e) methods of data collection, (f) analysis and synthesis of data, (g) ethical considerations, and (h) issues of trustworthiness. The section concludes with a brief summary.

Rationale for Qualitative Research Approach: Narrative Analysis

Qualitative research is well suited for this study, as the goal includes understanding the meaning and process of recovery from schizophrenia from the perspectives of those diagnosed with schizophrenia. Only in the past ten years have researchers employed qualitative methodologies, such as phenomenology (e.g., Davidson, 2003), for studying the subjective experiences of those with schizophrenia, psychosis, or other SMIs, as well as the experiences of their family members and professional providers (Boydell, Stasiulis, Volpe, & Gladstone, 2010). Narrative research is a particularly useful methodology for this study, as it aims to obtain a detailed, in-depth understanding of the personal life experiences, and meaning-making, of one individual or a small sample of individuals (Creswell, 2006; Riessman, 1993; Smith, 2000). Although narrative theory originated from the examination of literary texts, narrative analysis can be applied more broadly, including written (e.g., published memoirs, archival materials,

auto/biographies; Murray, 2008), spoken (i.e., as from an interview), and visual (e.g., art) accounts (Murray, 2008; Riessman, 2008). The aim of this study and research questions were consistent with the goal of narrative research as they sought to capture a subjective, detailed, understanding of individuals' life experiences of schizophrenia and recovery.

Rationale for Use of Published Narrative Data

There are numerous first person accounts of schizophrenia available, both published and unpublished (Ridgway, 2001). These provide a rich existing database for this inquiry, particularly those of recovery from schizophrenia, and are in the form of autobiographies, testimonies, diaries/journals, letters, and non-fictional stories (Hornstein, 2011). First person accounts were drawn from the journal, *Schizophrenia Bulletin*. The choice to draw on published narratives stemmed from a motivation to prioritize the voices of those who have already voluntarily written about their illnesses and recovery experiences. Moreover, Woods (2013) argued that the "First Person Accounts" subsection of *Schizophrenia Bulletin* is "the most prominent—if still desperately under-researched archive of schizophrenia narratives (p. 39). In other words, the basic argument for using existing text was that there is a great supply of it, largely unanalyzed. With analysis, these accounts were thought to provide many and specific insights into the process of recovery from schizophrenia, including facilitators, barriers, and definitions.

There are potential disadvantages to collecting and analyzing a sample of published narrative material. First, details about the social context surrounding the authors' first person accounts, and relevant background information, may not be available to the researcher, as they would be during an interview (Murray, 2008). Second, interpretive issues may occur, when working with written data, such as "imagined audience and other contexts implicated in

production” (Riessman, 2008, p. 22). However, these limitations, while noteworthy, do not outweigh the benefits of drawing from the rich and varied available texts.

Rationale for Sampling Method and Sample Size

Narrative research requires a minimum of one participant (Creswell, 2006); however, more than one participant is essential to demonstrate variation, as sample sizes are small and typically unrepresentative of the general population (Riessman, 1993). For the narrative analysis of written texts, little understanding or consensus regarding sample size exists. Two recently published, qualitative studies employing narrative analysis collected similar sample sizes: 20 (Angel et al., 2012) and 22 (Harrowing, Gregory, O’Sullivan, Lee, & Doolittle, 2012). Modeling these studies, I sampled 25 first person accounts of schizophrenia found in the *Schizophrenia Bulletin*. However, only 18 of the 25 were included in data analysis as they represented more contemporary accounts related to recovery (i.e., written 15 years prior or fewer) while those excluded from analysis were written more than 15 years prior. First person accounts were obtained for this study through *criterion-based sampling* (Bloomberg & Volpe, 2012), a type of purposeful sampling (Mertens, 2010). Simply, criterion sampling involves establishing a criterion and recruiting participants who meet that criterion (Mertens, 2010). The use of a criterion sampling strategy is well suited for narrative research as it allows the recruitment of participants who have all experienced a phenomenon of interest (Bloomberg & Volpe, 2012).

Because I was interested in individuals’ experiences of recovery from schizophrenia, my established criterion was a diagnosis of schizophrenia. Inclusion of a first person account in the data set from the *Schizophrenia Bulletin* occurred if (a) the essay was identified as a first person account, and (b) the abstract or introduction of an account broadly referenced a telling of recovery from schizophrenia. The choice to eliminate literature search results from other journals

came from the overwhelming result of 99 sources from *Schizophrenia Bulletin* alone. Other journals provided both dramatically fewer, and less salient accounts of recovery.

Demographics of the sample. Demographic information was collected and aggregated to the extent possible from the accounts. I sought to establish descriptive information about participants' ages, gender, occupations, locations, ethnic backgrounds, and age of first-episode psychosis and/or illness onset to contextualize these personal recovery narratives from schizophrenia.

Overview of Research Design

Methods of Data Collection

Procedures. Narrative research is not conducted in a rigid, step-wise approach (Creswell, 2006) and lacks a "standard set of procedures" (Riessman, 1993, p. 54), compared to other qualitative methodologies. First person accounts were directly obtained from the *Schizophrenia Bulletin* via the Internet. Once I determined the range of dates for the search, I included all first-hand accounts that met the criteria for use in this study: (a) the author of the first person account self-identified having schizophrenia; and (b) the title, abstract, or introduction of the first person account broadly referenced and/or alluded to a telling of recovery from schizophrenia.

Methods for Data Analysis and Synthesis

In the analysis of written material, the researcher is most interested in the language used to convey meaning to the reader and the way in which the author organizes events in the narrative (Riessman, 2008). The narrative researcher attends to both the structure and content of the narrative, as well as how the narrative relates to the broader context (Murray, 2008; Riessman, 1993). The overall goal of narrative analysis is to "reveal the underlying structure of narrative accounts that shape not only the way we account for our actions and those of others but

also our very identity” (Riessman, 1993, p. 70).

Riessman (1993) advises researchers to begin with the structural analysis of the narrative, including consideration of its organization; the primary elements and interconnections among them (Murray, 2008); the reasons for the ways in which the narrative was developed and under what conditions; the underlying, taken-for-granted assumptions of the story (Riessman, 2008); and the beliefs and values of the author (Murray, 2008). During analysis, Murray (2008) also encourages consideration of central themes, images, metaphors, and tone (i.e., “emotional flavour of the narrative”) portrayed in the text.

A narrative researcher must question (a) what the author is attempting to communicate to the reader, (b) how the author is doing so through the language used, (c) why the author is illustrating his or her experiences in this particular way, (d) what is achieved by telling the narrative that particular way, and (e) the effects of the particular telling on the reader (Riessman, 1993, 2008). Finally, the narrative researcher should consider any “gaps and inconsistencies that might suggest preferred, alternative, or counter-narratives” to the author’s story (Riessman, 2008, p. 11), and give attention to ostensibly trivial details that may reflect underlying, taken-for-granted assumptions of the narrative account.

I employed a *thematic approach* (Bamberg, 2010), as I was interested in the themes of recovery that were present in the first person accounts. Moreover, first person accounts are often analyzed thematically (Riessman, 2008). I facilitated an “analysis of narratives,” as distinguished from, “narrative analysis” (Polkinghorne, 1995, p. 12). Analysis of narratives involves developing themes, based on theoretical models or paradigms, which apply to the majority of first person accounts, while narrative analysis involves obtaining accounts of events and organizing them into a story based on a specific plot (Creswell, 2006, p. 54). Because the

analysis of narratives is an inductive process, existing research questions may be modified, while new questions may arise during the very analysis (Riessman, 1993). An analysis of narrative data is guided by both theoretical assumptions, and the researcher's beliefs and assumptions, alongside openness to "new ideas and challenges" (Murray, 2008, p. 121).

The analysis of first person accounts involved two stages, with a detailed, systematic reading of the accounts preceding both analytic stages (Murray, 2008). The analytic stages, as outlined by Murray (2008), are described as follows:

Stage 1. The first stage of narrative analysis was descriptive and consisted of briefly summarizing each narrative account. Summaries identified the significant features (e.g., beginning, middle, end); underscored important issues raised in the account; and recognized connections among various parts of each narrative, including different sub-plots (Murray, 2008). Overall, the summaries illustrated and emphasized the elements of the first person accounts in which I was most interested.

Next, I read the summaries to obtain an initial understanding of the primary and common concerns raised within and across narratives (Mishler, 1986). Based on the focused reading of the summaries, I developed and applied a *coding frame* to all first person accounts, so as to "capture the overall meaning of the narratives and the various particular issues raised within each" (Murray, 2008, p. 120).

The coding frame was developed according to the six phases of thematic analysis as outlined by Braun and Clarke. After familiarizing myself with the data through several focused readings of each account and accompanying summaries, I completed the second phase of thematic analysis by systematically coding noteworthy and meaningful features of each personal account, generating initial codes. Next, codes were sorted into potential themes. Themes were

then reviewed by verifying that each coded extract of data accurately reflected the meaning of the relevant themes, resulting in a *codebook* (see Appendix) that fit and represented the data set (Ryan & Bernard, 2000, as cited in Braun & Clarke, 2006, p. 98). Phase five involved further refining themes and subsequently naming and defining themes, as well as identifying subthemes. The final phase of analysis was comprised of producing the Results section, where evidence of themes was presented with vivid examples. Resulting categories, themes, and subthemes were retained in the results if they occurred in at least six first person accounts, approximately one-third of the entire data set.

Stage 2. The second stage of narrative analysis involved interpreting the narrative accounts in the context of the larger, theoretical literature sources (Murray, 2008) referenced earlier in this section. As I was interested in how individuals diagnosed with schizophrenia experienced the recovery process, the primary issue in the reading of the first person accounts was how the authors defined recovery, described their processes of recovery, and what they characterized as integral to the recovery process. I connected the first person accounts to the current, theoretical models of recovery as well as highlighted findings contradictory and divergent from the existing literature.

Ethical Considerations

It is of utmost importance in all research to protect participants from harm, protect their rights, and ensure confidentiality (Bloomberg & Volpe, 2012; Mertens, 2010). However, no ethical threats were anticipated given that the research sample was comprised of narrative text, and did not engage human participants. Because the first person accounts were published and available to the public, informed consent from authors for the use of their accounts in the study was not required. Nonetheless, research-related records and data were stored securely on a

password-protected laptop.

Issues of Trustworthiness

In qualitative research, trustworthiness refers to taking measures of quality control against biases that may emerge throughout any phase of the study, including data collection and analysis (Bloomberg & Volpe, 2012). Narrative researchers are particularly concerned with both the validity of the participant's narrative, and the validity of the researcher's analysis (Riessman, 2008). However, given that the study was framed from a constructionist perspective, corroborating the first person accounts with other sources of evidence was not necessary; it was more important to understand the meanings of the accounts to their authors (Riessman, 2008).

Several measures of trustworthiness were employed in the study, including *credibility*, *transferability*, *dependability*, *confirmability* (Bloomberg & Volpe, 2012), *coherence* (Riessman, 2008), and *authenticity* (Guba & Lincoln, 1989):

Credibility. Credibility assesses the extent to which the researcher's depiction of the participants' perceptions matches that of what they actually expressed (Bloomberg & Volpe, 2012; Mertens, 2010). To ensure credibility, *peer debriefing* (Bloomberg & Volpe, 2012) was employed to improve the accuracy of my depiction of the authors' perceptions. I asked a fellow doctoral candidate of my graduate school cohort to examine and question my thematic analysis and resulting themes. Specifically, the debriefing peer first read Braun and Clarke's (2006) writings on thematic analysis to gain an understanding of the process. Next, the debriefing peer and I reviewed initial codes generated from the data and resolved discrepancies regarding the extent to which the codes represented data extracts. Then, the debriefing peer and I reviewed themes that emerged from initial codes, resolving similar discrepancies regarding the extent to which the themes represented groups of initial codes. We also reviewed initial thematic maps to

assess the extent to which they reflected the entire data set. To maintain credibility, I also attended to instances of *negative case analysis* (Mertens, 2010; Bloomberg & Volpe, 2012), establishing themes of both convergence and divergence (Riessman, 2008) by reporting on variation among themes and discrepant findings from emerging patterns across cases.

Transferability. Transferability refers to the degree of similarity between the context of the study's findings, the receiving context of the study's findings, and other contexts as perceived by the reader (Bloomberg & Volpe, 2012). Transferability assesses the extent to which the researcher has allowed the reader to make judgments regarding similarity by providing adequate description about the context of the study (Mertens, 2010).

In narrative research, transferability is achieved through coherence (Riessman, 1993). The three types of coherence are (a) *global*, (b) *local*, and (c) *themat* (Agar & Hobbs, 1982). Optimal coherence occurs when all three types are present in a narrative. *Global* coherence pertains to the general goals that are achieved by the author through the writing of the first person account. "*Local* coherence is what a narrator is trying to effect in the narrative itself, such as the use of linguistic devices to relate events to one another" (Riessman, 1993). *Themat* coherence refers to recurring themes within the narrative.

Dependability and confirmability. Although change is anticipated in qualitative research (Mertens, 2010), both expected and unexpected findings should be monitored and recorded, demonstrating dependability of the research. In this study, I thoroughly documented data collection and analysis procedures, a process akin to an audit (Bloomberg & Volpe, 2012; Riessman, 2008). I memoed self-observations of my analytic and interpretative processes, highlighting how change developed (Susan Hawes, personal communication, May 6, 2013). These memos satisfied measures of confirmability, as they verified the soundness of my

interpretations, and the series of events that produced those interpretations (Mertens, 2010).

Authenticity. No matter the type of narrative data, researchers can never fully know the author's direct experience (Riessman, 2008); all narratives are "constructed by socially situated individuals from a perspective and for an audience" (p. 23). To promote and maintain authenticity throughout this study, I continually considered the ways in which the narrative texts represented the authors' viewpoints at certain times, and in the context of a variety of diversity factors (Mertens, 2010). Additionally, I maintained a log of decisions and inferences made as I completed the research study, to "foster ongoing reflexivity—critical self-awareness about how the research was done and the impact of critical decisions made along the way" (Riessman, 2008, p. 191).

Summary

This section provided a description of the study's methodology. Narrative analysis was selected as a research methodology to explore the narratives of recovery by individuals diagnosed with schizophrenia. Eighteen participants diagnosed with schizophrenia comprised the purposefully selected sample. Implemented data collection methods consisted of collecting and analyzing published, first person accounts. All measures of trustworthiness were satisfied by the research study through a variety of techniques, including peer debriefing, negative case analysis, and creating an audit trail.

Results

Although I sampled 25 first person accounts of schizophrenia found in the *Schizophrenia Bulletin*, only 18 of the 25 were included in data analysis as they represented more contemporary accounts related to recovery (i.e., written 15 years prior to 2016 or less) while those excluded from analysis were written more than 15 years prior to 2016. Table 1 depicts information about

participants' age at the time the account was completed, gender, country where illness and/or recovery was experienced, occupation/credentials, and age of illness onset. Demographic information was collected as available and reported in the first person accounts.

Table 1

Demographics of Participants

| P | Age | Gender | Country | Occupation/Credentials | Age of Onset |
|----|-----|--------|-------------------|---|---|
| 1 | NR | M | U.K. | Doctoral-level mental health academic and researcher | NR |
| 2 | NR | M | CA, U.S. | Veteran | NR |
| 3 | NR | M | NR | Ph.D. | NR |
| 4 | NR | F | Glasgow, Scotland | Former radiotherapy student, attended university at time of writing | NR |
| 5 | 45 | M | Kolkata, India | Undergraduate degree in chemical engineering, teaching position at engineering college, Faculty cum Content Developer (Mathematics), Researcher of Environmental Engineering, Faculty of Chemical Engineering | Onset during final year of undergraduate school |
| 6 | NR | NR | NH, U.S. | College graduate, employment in psychiatric research | NR |
| 7 | NR | F | NR | Full-time employment (unspecified) | NR |
| 8 | NR | M | NR | Some college, employment during college | NR |
| 9 | NR | F | U.K. | Social worker, researcher, senior lecturer, Ph.D. | 18 |
| 10 | NR | M | U.S. | Undergraduate degree, attended graduate school, social worker | Onset while attending undergraduate school |

(table continues)

Table 1 (continued)

Demographics of Participants

| P | Age | Gender | Country | Occupation/Credentials | Age of Onset |
|----|-----|--------|------------|--|--|
| 11 | NR | NR | U.S. | Master's degree in electrical engineering, currently searching for employment | Onset while attending undergraduate school |
| 12 | 40s | M | Canada | Readaotion Psychosociale (PSR) Canada Ontario Chapter board member, Acceptance and Commitment Therapy peer support worker, graduate degree | Onset while attaining Master's degree in Organic Chemistry |
| 13 | NR | M | U.S. | Bachelor's degree in psychology, planned to apply to graduate school at time of writing | Onset during undergraduate school likely |
| 14 | 50 | M | U.S. | Former programmer (unspecified) | 26 |
| 15 | NR | F | U.S. | NR | Early 20s |
| 16 | 30s | M | Arnold, MD | Joined local volunteer fire department and elected vice president | 19 or 20 during undergraduate school |
| 17 | NR | F | U.S. | Former basic education and English teacher at alternative high school | 31 during graduate school |
| 18 | 29 | M | U.S. | Bachelor's degree in biology and psychology, graduate school for research assistantship studying pharmacology, planned to apply to graduate programs again within a month of time of writing | 16 |

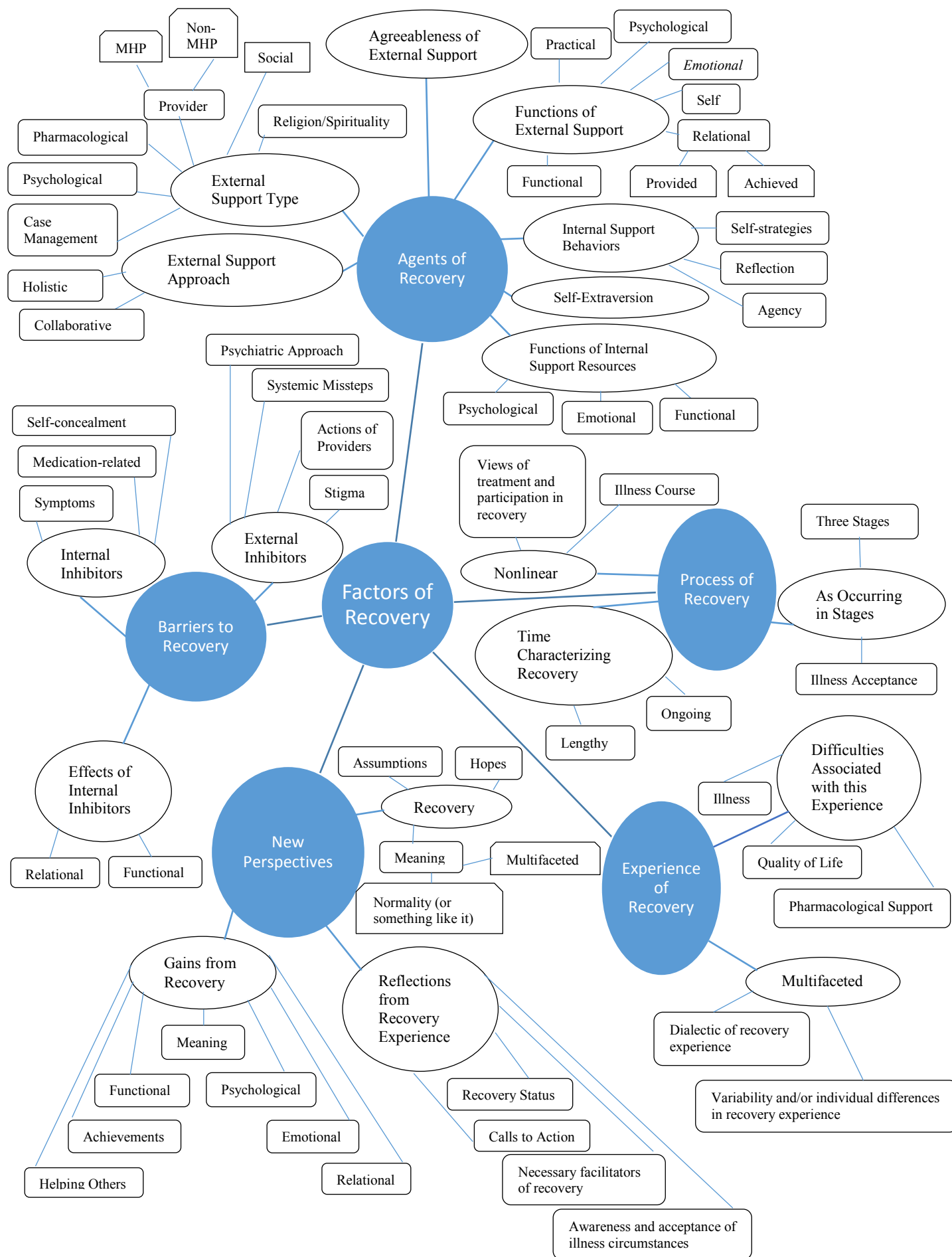
Note. P = Participant, M = Male, F = Female, NR = Not Reported

A summary of the 18 research participants' demographic information is offered. Five of

18 participants reported their age at the time of writing the account: one of the five was 29 years old, one of the five was in his 30s, two of the five participants were in their 40s, and one of the five was 50 years of age. Eleven of the 18 study participants identified as male, five participants identified as female, and two participants did not indicate their gender identification. Fifteen of the 18 study participants identified the country within which they experienced schizophrenia and/or recovery, while three participants did not report this information; 10 of 15 participants indicated the U.S., while the remaining five indicated a country outside of the U.S.

Seventeen of 18 research participants reported information related to occupation and/or credentials. Three of 17 participants reported having a doctoral level degree. Two of 17 reported having a graduate-level degree (e.g., Master's). Six of 17 participants indicated having an undergraduate degree. One participant reported having some college experience, while another participant attended university during the time of writing the first person account. Two of seventeen participants planned to attend graduate school at the time of writing their first person accounts. Eight of 17 participants reported current employment, five of 17 participants reported past employment, and one participant reported a current search for employment. Four of 17 participants indicated past experience in either undergraduate and/or graduate school.

Eleven of 18 participants with schizophrenia indicated an age or time of illness onset, while seven participants did not report such information. Two of eleven participants reported onset to occur during their teens (i.e., 16 and 18 years of age), two participants reported onset occurring in their 20s, and one participant reported onset occurring at age 31. Five of 11 participants reported onset occurring while attaining their undergraduate degree, and two participants reported onset while attaining their graduate degree.



On the basis of the thematic analysis of these 18 personal accounts written by individuals diagnosed with schizophrenia, I found five categories of themes that comprise the *Factors of Recovery*: (a) Agents of Recovery, (b) Process of Recovery, (c) Experience of Recovery, (d) New Perspectives, and (e) Barriers to Recovery. These categories are understood as “factors” given that they encompass a multitude of concepts, in the form of themes and subthemes, which emerged from the data. Figure 1 depicts the categories, themes, and subthemes.

Agents of Recovery

Within the theme of *Agents of Recovery*, I found seven subthemes: (a) External Support Approach, (b) External Support Type, (c) Agreeableness of External Support, (d) Functions of External Support, (e) Internal Support Behaviors, (f) Self-Extraversion, and (g) Functions of Internal Support Resources.

External support approach. Table 2 depicts the subthemes within *Agents of Recovery: External Support Approach*. I defined this theme as “any reference to a framework or approach of mental health care that is viewed as beneficial to, preferred by, and/or facilitates recovery for the diagnosed individual.” The subtheme, *Holistic* included narratives such as this one:

Being able to be in a private recovery center was the conduit to recovery. Having connections to housing services, higher education and education grant monies, to employment, to obtain SSI and Medicaid were instrumental. Getting a job in psychiatric research has been vital. Recovery involves the support of family, government, community, and beneficial psychiatric services. Recovery is not just one element, but rather many elements that lead to the wheel of health.

The subtheme *Collaborative* pertained to responses such as, “Service users should be central to decision making about their own care and treatment because working in partnership leads to better outcomes for service users and their families.”

Table 2

Dimensions of Theme One – Agents of Recovery: External Support Approach

| Theme | Subthemes |
|--|---------------------------------|
| Agents of Recovery: External Support Approach | 1. Holistic 2. Collaborative |

External support type. Table 3 depicts the subthemes within *Agents of Recovery: External Support Type*. This theme was defined as “any reference to a type of support, associated with the mental health field or not, that is viewed as beneficial to, preferred by, and/or facilitates recovery for the diagnosed individual.”

Case management was represented in responses such as, “Help may be needed to support basic needs like cooking, keeping clean, and other household tasks. Giving and receiving practical support are inherently related to our care-giving mentality.” The *Psychological* subtheme of support may be seen in responses such as:

I started seeing another psychiatrist outside the hospital who fortunately was very caring. He listened to me patiently, got me on the right dose of medication, and after 6 months diagnosed me with schizophrenia. He described to me what the illness was and gave me literature references to read to help me understand the illness.

The *Pharmacological* subtheme included responses such as:

I have been taking Zyprexa for three years, and it seems to be working beautifully, except for the extra twenty pounds of fat I’m carrying around. However, I wouldn’t change it for anything. I have continued to notice steady improvement in my condition over the last three years, both for positive and negative symptoms.

The subtheme *Provider* may be seen in responses representing support from both mental health

professionals (e.g., “My psychologist noticed that when I talked about some of my books and issues I knew about, I became much less terrified and able to think more clearly. This motivated me to write again and set goals”), and non-mental health professionals (e.g., “I found others as well, leaders and guides, who gave me valuable advice on how to live. One was Christian writer C. S. Lewis. He said, ‘What a sad world it would be with no one to look up to’”).

The subtheme *Social* was captured by responses such as the following:

I cannot stress the importance of having a supportive family and girlfriend during my time in the psych ward. My family was first in helping me come to realize that I suffered from schizophrenia. The book, *Diagnosis Schizophrenia*, which my family gave me, was particularly helpful.

Religion/Spirituality pertained to responses such as, “Almighty was slowly helping me and making me a brilliant researcher and teacher.”

Table 3

Dimensions of Theme Two – Agents of Recovery: External Support Type

| Theme | Subthemes |
|--|--|
| Agents of Recovery: External Support Type | <ol style="list-style-type: none"> 1. Case management 2. Psychological 3. Pharmacological 4. Provider <ol style="list-style-type: none"> a. Mental Health Professional (MHP) b. Non-Mental Health Professional 5. Social 6. Religion/Spirituality |

Agreeableness of external support. Table 4 depicts the theme, *Agents of Recovery: Agreeableness of External Support*. I defined this theme as “any reference to agreeableness, a personality characteristic understood by the Five-Factor Model, demonstrated by a support type that is viewed as beneficial to, preferred by, and/or facilitates recovery for the diagnosed individual.” External support types demonstrating agreeableness was represented in responses such as, “Oppressive doctors or therapists were not helpful, but the ones who respected my efforts at recovery were. Case workers were there for social support and advice.”

Table 4

Dimensions of Theme Three – Agents of Recovery: Agreeableness of External Support

 Theme

 Agents of Recovery: Agreeableness of External Support

Functions of external support. Table 5 depicts the subthemes within *Agents of Recovery: Functions of External Support*. This theme was defined as “types of results and functions, both intended and not, of any support types identified that are viewed as beneficial, preferred by, and/or facilitate recovery for the diagnosed individual.” *Practical* was represented in responses such as, “A female social worker assisted in getting me into a private psychiatric recovery center. I had a room to myself, which allowed me some peace. A worker for that hospital assisted my getting on SSI and Medicaid.” The subtheme *Psychological* may be seen in responses such as “After psychotic episodes...my parents decided to try me on a new antipsychotic, this time Clozaril....it worked, and the negative symptoms lessened dramatically.” *Emotional* was captured by responses such as the following:

Along with food and daily visits from family and friends, music helped keep me relaxed, even when I was receiving messages from all around me. One song in particular helped to calm me down...I remember an attendant complimenting my taste in music, which made me feel like a person again.

Psychological gains are qualitatively different than emotional gains from recovery. Emotional gains refer to traditional improvements in emotional well-being and experience of positive emotions, while psychological refers to anything symptom related; improvements in cognitive and/or neuropsychological functions; and more psychologically-minded concepts related to change, such as insight, enlightenment, willpower, and motivation.

The subtheme of *Self*, pertaining to changes in the self as a result of external support types and their functions, was captured in responses such as, “A lot of effort, time, and thought went into my recovery. My team took excellent care of me while I made my way back to normality. These people found me, which enabled me to find myself.”

The subtheme of *Relational* pertained to relational functions *Provided* by the external support types, as exemplified by responses such as the following: “Perhaps the most influential has been meeting regularly with my supervisor, an anthropologist who studies the lived experience of psychiatric illness. She has aided my journey to recovery—by listening to my experience, often validating something I say...” The subtheme of *Relational* also referred to relational functions *Achieved* by the diagnosed individual as a result of the external support types, represented by responses such as, “Here, I met new friends who accepted me. My attention shifted to pleasure and was increased through meeting new friends...”

The *Functional* subtheme, referring to the diagnosed individual’s ability to engage in active and purposeful activities, including occupation-related activities, emerged from responses such as, “Whilst having cognitive behavioral therapy, a support worker was put in place to go out with me, and I was gradually exposed to the fear I had of going out.” An example of an occupation-related outcome as a result of external support types may be seen in the following:

I was referred to National Institute of Mental Health and Neurosciences, Bangalore, India. I accompanied my parents to NIMHANS, Bangalore where we stayed in the family ward to be closely observed by doctors....we stayed there for 1 month as the new medication was administered. After treatment, we came back to Kolkata and I got a job as a researcher in one of the most reputed institutes of India.

Table 5

Dimensions of Theme Four – Agents of Recovery: Functions of External Support

| Theme | Subthemes |
|--|---|
| Agents of Recovery: Functions of External Support | <ol style="list-style-type: none"> 1. Practical 2. Psychological 3. Emotional 4. Self 5. Relational <ol style="list-style-type: none"> a. Provided b. Achieved 6. Functional |

Internal support behaviors. Table 6 depicts the subthemes within *Agents of Recovery: Internal Support Behaviors*. I defined this theme as “any reference to an action, or type of action, initiated by the diagnosed individual, that is viewed as beneficial, preferred, and/or facilitates recovery.” The subtheme of *Self-strategies* may be seen in responses such as, “I felt hope for the first time in so long. I learnt to cope with my symptoms and implement strategies to reduce them.” *Reflection* included responses such as, “After sometime reflecting and regrouping, I was determined to find a meaningful job and contribute positively and constructively to society.” The subtheme of *Agency* was exemplified in responses emphasizing the diagnosed individual’s demonstration of choice in shaping his or her own life, such as the following:

Joan of Arc has proven the perfect role model for how to live with faith as a schizophrenic patient. Even though her experiences were admittedly delusional, her life has demonstrated the power of faith. Although others, even during her own life, did not believe in what she had seen, she still had been able to arrive at a state of being in which she exercised a profound effect on others. I have taken the lessons of her life and applied

them to my own—to live an inspiring life upholding belief and the spirit and to live for a cause other than purely one's own self-interest.

Table 6

Dimensions of Theme Five – Agents of Recovery: Internal Support Behaviors

| Theme | Subthemes |
|---|--|
| Agents of Recovery: Internal Support Behaviors | 1. Self-strategies 2. Reflection 3. Agency |

Self-extraversion. Table 7 depicts the theme *Agents of Recovery: Self-extraversion*. I defined this theme as “any demonstration of extraversion, a personality characteristic understood from the Five Factor Model, by the diagnosed individual that facilitates recovery and/or moves the individual to attain his/her aims associated with recovery.” Extraversion was demonstrated in responses such as, “But things took a turn for the worse when I was diagnosed with schizophreniform/schizophrenia. I pushed my way through.”

Table 7

Dimensions of Theme Six – Agents of Recovery: Self-extraversion

 Theme

 Agents of Recovery: Self-extraversion

Functions of internal support resources. Table 8 depicts the subthemes within *Agents of Recovery: Functions of Internal Support Resources*. I defined this theme as “types of results and/or functions, both intended and not, of any actions initiated by and/or personality traits of the diagnosed individual that are viewed as beneficial, preferred, and/or facilitate recovery.” The subtheme of *Psychological* may be seen in responses such as the following:

Now the only thing left to get back in shape was my mind. I could barely concentrate for a few minutes, let alone the prolonged focus necessary to be a successful student at University of Michigan. To get back in shape, I decided that I would read *East of Eden*, quite a lengthy book and a rather ambitious goal for me at the time. During the beginning, I could only read a few pages at a time, but later, I was able to read entire chapters without losing focus. Eventually, my concentration went back to normal.

Emotional included responses such as, “my search for alternative approaches to manage this illness has helped me stay in stable full-time employment (since 2005) and to improve my general well-being and happiness and avoid hospitalizations.” The subtheme of *Functional*, referring to the diagnosed individual’s ability to engage in meaningful and purposeful, independent activities, including occupation-related; may be exemplified in responses such as:

I was changing jobs frequently due to my restlessness and anxiety. I thought judgment day will never come to my life. I was depressed, weak, and emaciated. Again, due to my resilience, I got a teaching job at a reputed engineering college.

Table 8

Dimensions of Theme Seven – Agents of Recovery: Functions of Internal Support Resources

| Theme | Subthemes |
|---|---|
| Agents of Recovery: Functions of Internal Support Resources | 1. Psychological 2. Emotional 3. Functional |

Process of Recovery

Within the theme of Process of Recovery, I found three subthemes: (a) Nonlinear, (b) As Occurring in Stages, and (c) Time Characterizing Recovery:

Nonlinear. Table 9 depicts the subthemes within *Process of Recovery: Nonlinear*. I defined this theme as “any reference to aspects of the process of recovery that are nonlinear in nature.” The subtheme *Illness course* included responses such as, “I have just spent a month in a psychiatric ward. In fact, as I write this, I’m still here. It’s my third relapse in 10 years, and the first time it lasted for nearly a year.” *Views of treatment and participation in recovery* as a subtheme pertained to responses such as, “It took me a long time for me to admit to myself that I had been mentally ill, and that I needed to take some type of psychiatric medication for the rest of my life.”

Table 9

Dimensions of Theme Eight – Process of Recovery: Nonlinear

| Theme | Subthemes |
|--------------------------------|--|
| Process of Recovery: Nonlinear | 1. Illness course 2. Views of treatment and participation in recovery |

As occurring in stages. Table 10 depicts the subthemes within *Process of Recovery: As Occurring in Stages*. I defined this theme as “any reference to aspects of the recovery process that are characterized as occurring as stages and/or descriptions of the stages associated with the recovery process.” The subtheme *Three stages* included responses referencing stage one, two, or three of the recovery process. Generally throughout multiple accounts, the process of recovery was described as occurring in three stages. Responses exemplifying one of three stages included, “I had a psychotic episode, and the treatment required medication in the hospital. Once that happened, I went to the next stage of my recovery,” and, “Stage 2 lasted another 8 years. I became disillusioned with psychiatric professionals, and though I continued to see them for medication and counseling, I no longer respected them.” The subtheme *Illness acceptance* was captured in responses such as the following:

At this point in time, I was in the early stages of acceptance and did not want to talk about my decisions and actions at all. Although I was struggling to accept my new reality (diagnosis etc.), I just spared a moment here and there to think about what life would be like to be mentally stable again. These ideas of being healthy gave me courage and this made me smile again.

Table 10

Dimensions of Theme Nine – Process of Recovery: As Occurring in Stages

| Theme | Subthemes |
|--|--|
| Process of Recovery: As Occurring in Stages | 1. Three stages 2. Illness acceptance |

Time characterizing recovery. Table 11 depicts the subthemes within *Process of Recovery: Time Characterizing Recovery*. I defined this theme as “any reference to the quality of the time associated with the recovery process.” The subtheme *Ongoing* may be seen in responses such as the following:

The last 10 years has not been easy. There have been hospital stays, numerous medication changes, and major lifestyle changes. All of that has brought me to today where I am in a state of constant recovery. I am fully aware that recovery never ends. As simple as it may sound: I must follow the rules of recovery. Not for the next month or 6 months, but for the rest of my life.

Lengthy included responses such as, “Recovery to me was a mirage. Recovery was so slow.”

Table 11

Dimensions of Theme Ten – Process of Recovery: Time Characterizing Recovery

| Theme | Subthemes |
|--|--------------------------|
| Process of Recovery: Time Characterizing Recovery | 1. Ongoing 2. Lengthy |

Experience of Recovery

Within the theme of Experience of Recovery, I found two subthemes: Difficulties

Associated with this Experience and Multifaceted:

Difficulties associated with this experience. Table 12 depicts the subthemes within *Experience of Recovery: Difficulties Associated with this Experience*. I defined this theme as “any reference to types of difficulties associated with the experience of recovery.” *Illness* was captured in responses such as the following:

I sometimes hear negative voices too. They can be insulting, and they can tell me to kill myself. This is part of the struggle. It’s something I don’t like to talk about. When I hear these negative voices, I do my best to stimulate my brain and be active, or I try to ignore them.

The subtheme *Pharmacological support* was exemplified in responses such as the following:

Zyprexa [sic] helps me tremendously....notwithstanding, I have gained so much weight I have to go off of it....Zyprexa makes me crave for food that is bad for me. I will sit down for a meal, and when I finish, oftentimes, I will start on another meal—something has to be done.

Quality of life was represented in responses referring to difficulty with or loss of meaningful, purposeful activities, including occupational, such as, “What proved hardest was to watch as my dreams died one by one.”

Table 12

Dimensions of Theme Eleven – Experience of Recovery: Difficulties Associated with this Experience

| Theme | Subthemes |
|--|--|
| Experience of Recovery: Difficulties Associated with this Experience | 1. Illness 2. Pharmacological support 3. Quality of Life |

Multifaceted. Table 13 depicts the subthemes within *Experience of Recovery*:

Multifaceted. I defined this theme as “any reference to aspects of the recovery experience that are mixed, complex, variable, or individualized in quality and/or nature.” The subtheme *Dialectic of recovery experience* emerged from responses such as the following:

My illness, in and by itself, appeared to have destroyed me. But stepping back to see the broader picture, I saw that my painful trial of suffering had had a greater purpose.

Though I continue to have setbacks and struggles, I am singing a song of a new and transformed life.

Another emergent subtheme subsumed under this theme was *Variability and/or individual differences in recovery experience* exemplified in responses such as, “When one discovers how to live a life devoted to staying well, one discovers a peacefulness to life and serenity that once discovered is glaringly obvious, yet each path to that state is unique to each person.”

Table 13

Dimensions of Theme Twelve – Experience of Recovery: Multifaceted

| Theme | Subthemes |
|--------------------------------------|--|
| Experience of Recovery: Multifaceted | 1. Dialectic of recovery experience 2. Variability and/or individual differences in recovery experience |

New Perspectives

Within the theme of New Perspectives, I found three subthemes: Gains from Recovery, Recovery, and Reflections from Recovery Experience:

Gains from recovery. Table 14 depicts the subthemes within *New Perspectives: Gains from Recovery*. I defined this theme as “any type of positive change and/or gain resulting directly from the process of recovery.” The subtheme *Meaning* included responses such as, “True, my illness had devastated me. It had crushed me in heart, mind, and spirit. The rebuilding of my life took time, 25 years in fact. But despite serious illness, I had found meaning.” The subtheme *Emotional* may be seen in responses such as, “My life seemed to take on new meaning and purpose. Things came to me naturally, and I really enjoyed what I was doing.”

The subtheme *Psychological* was referenced in responses such as, “Why should I feel ashamed of who I am? The bad experiences and rough times came back in flashbacks. I didn’t regret anything. They had made me who I am. I am enlightened.” The subtheme *Functional* referred to gains that were related to engagement in purposeful and/or occupation-related activities and/or improved level of functioning in life. This subtheme was reflected in responses such as the following:

Since 2011, I am continuously on medication. I have had regularly recurrent episodes even then. However, they have increasingly been very short term (a couple of days at the most). I have never been hospitalized and live independently, even in a foreign country.

Achievements referred to gains that were specifically labeled as such and/or as successes, which may be seen in responses such as, "I have actually had quite a lot of success in recent years. I joined my local volunteer fire department, and I was elected vice president this past year."

Relational was exemplified in responses such as the following:

I especially connected with a 70-year-old woman....recently, I took her with me to the chaplaincy group, where she said a little about herself and her 2 sons, which was the first group she had attended in some months. This helped us both a lot, and we have become good friends.

The subtheme *Helping others* was exemplified in responses such as the following:

The reason that I have written this essay is because I want to help others in similar situations, and by writing this all out I expand my awareness from the thoughts generated. I think this essay is crucial for both the learning disabled and mentally ill. All we want is a chance, a level playing field.

Table 14

Dimensions of Theme Thirteen – New Perspectives: Gains from Recovery

| Theme | Subthemes |
|--|--|
| New Perspectives: Gains from Recovery | <ol style="list-style-type: none"> 1. Meaning 2. Emotional 3. Psychological 4. Functional 5. Achievements 6. Relational 7. Helping others |

Recovery. Table 15 depicts the subthemes within *New Perspectives: Recovery*” I defined this theme as “any reference to new types of perspectives associated with any aspect of the concept of recovery that have largely resulted from the process and experience of recovery.” The subtheme *Assumptions* of recovery emerged from responses such as, “It is not easy, but ongoing victory is possible.” The subtheme *Meaning* of recovery is divided into two types of new perspectives. The first, *Multifaceted*, was captured in responses that acknowledged the complexity of recovery, such as the following:

Recovery can mean many things,’ I said. ‘Recovery can be a process as well as an end. It is not necessarily the disappearance of symptoms, but the attainment of meaningful goals for one’s life. Recovery means finding hope and the belief that one may have a better future. It is achieving social integration. It is finding a purpose in life and work that is meaningful. Recovery is having clear direction.

The second, *Normality (or something like it)* was exemplified by responses such as, “My illness has been abated, I am productive again, and I plan on having a normal existence for the rest of my life.” Another example of this subtheme may be seen in responses such as, “Recovery to me means that, even if the delusions are not completely gone, I am able to function as if they are.”

The subtheme *Hopes*, referring to future hopes related to recovery, was captured in responses such as the following:

I am now doing well in a way that is meaningful to me. I work, study and have recently gotten engaged to someone I met during recovery. I still take medication every day but I hope to not have to do this forever.

Table 15

Dimensions of Theme Fourteen – New Perspectives: Recovery

| Theme | Subthemes |
|----------------------------|--|
| New Perspectives: Recovery | <ol style="list-style-type: none"> 1. Assumptions 2. Meaning <ol style="list-style-type: none"> a. Multifaceted b. Normality (or something like it) 3. Hopes |

Reflections from recovery experience. Table 16 depicts the subthemes within *New Perspectives: Reflections from Recovery Experience*. I defined this theme as “any reference to types of reflections and/or lessons learned as a result of the process and experience of recovery.” The subtheme *Necessary facilitators of recovery* may be seen in responses such as the following:

Having a support network is essential to making a recovery to a normal life, and I have my wife to thank the most. I met her online in 2005, and she is always there when I am having trouble and need someone to center me.

The subtheme *Calls to action* referred to any direct recommendation to the mental health field by the diagnosed individual, exemplified in responses such as the following:

Involving service users in the development of the professional framework redefines the relationships between service users and professionals. In order to allow professionals to embrace the user voice, there must be a breakdown of the boundaries between professional knowledge and user expertise and recognition of both as blurred and incomplete. There must be a rebalance of power and a redefinition of what constitutes valid knowledge, whether it is derived from experiential, practice, or academic wisdom.

Awareness and acceptance of illness circumstances included responses such as, “My resilience increased throughout the [psychotherapy] sessions and by the time they finished I had a better

opinion of myself and was able to understand that psychosis was an illness that could be treated,” as well as, “I was in denial about my mental illness for years. Now I accept it as a lifelong condition.” The subtheme *Recovery status*, as acknowledged by the diagnosed individual, was reflected in responses such as, “Even now, I am not totally cured. But I have improved.”

Table 16

Dimensions of Theme Fifteen – New Perspectives: Reflections from Recovery Experience

| Theme | Subthemes |
|---|---|
| New Perspectives: Reflections from Recovery Experience | <ol style="list-style-type: none"> 1. Necessary facilitators of recovery 2. Calls to action 3. Awareness and acceptance of illness circumstances 4. Recovery status |

Barriers to Recovery

Within the theme of Barriers to Recovery, I found three subthemes: External Inhibitors, Internal Inhibitors, and Effects of Internal Inhibitors:

External inhibitors. Table 17 depicts the subthemes within *Barriers to Recovery: External Inhibitors*. I defined this theme as “any external source that prevents and/or delays the diagnosed individual from engaging in the process and experience of recovery.” The subtheme *Actions of providers* may be seen in responses such as the following:

My first doctor that I will call doctor A barely saw me and did not really talk to me. He just prescribed Risperdal with no explanation. If someone had sat me down then and spent a couple of hours for a couple of days, maybe I would not have had the type of problems that I had.

The subtheme *Stigma* included responses such as, “I believed that I had ‘kicked’ the disease. I even threw the remainder of my antipsychotics down the toilet in fear that a nosey visitor might notice them in the bathroom medicine cabinet and start making assumptions.” *Psychiatric approach* emerged from responses such as, “Hospital wards can hinder recovery because the patients in [sic] and nurses are not sharing compassionate conversation and are left to watch the television. They do not always feel safe-like places.” Another example of Psychiatric approach

as a subtheme may be seen in the following response:

More worryingly, when in hospital, violence is sometimes used as a tool for getting noncompliant patients to take their medication, usually via depot injection. This violence is often conceived of as right, as just, and in the patient's best interest. Certainly, many nurses I have spoken to have not only said that they do not like administering forcible injections but also say that they have a duty of care. Violence as care is an oxymoron and hides the institutionalized abuse of people with schizophrenia and mental health problems.

The subtheme *Systemic missteps* referred to general weaknesses of the systems that interact with the diagnosed individual that result in unintended oversights and consequences (e.g., misdiagnosis, lack of illness detection). Examples of systemic missteps may be seen in responses such as, "Daily evaluations by the psychiatrists were fairly simple, and I still do not believe they had any valid data on the actual details of my situation at the time," and, "I also began to believe that my phone was being tapped. My friends insisted I was mistaken. But no one knew enough to realize anything was wrong."

Table 17

Dimensions of Theme Sixteen – Barriers to Recovery: External Inhibitors

| Theme | Subthemes |
|--|---|
| Barriers to Recovery: External Inhibitors | <ol style="list-style-type: none"> 1. Actions of providers 2. Stigma 3. Psychiatric approach 4. Systemic missteps |

Internal inhibitors. Table 18 depicts the subthemes within *Barriers to Recovery: Internal Inhibitors*. I defined this theme as “any aspect related to the diagnosed individual’s actions and/or self-experience that prevents and/or delays him or her from engaging in the process and experience of recovery.” *Medication-related* as a subtheme emerged from responses such as the following:

During each psychotic episode, my family tried to get me medical help. Medications were prescribed, but I refused to take them. I didn’t believe anything was wrong with me. I thought I was just having an unusual experience. I didn’t want to take anything that altered my brain—those pills were for crazy people.

The subtheme *Self concealment* referred to instances where diagnosed individuals avoided disclosing aspects of their illness experience to MHPs, for example. Reasons for non-disclosure varied (e.g., fear of hospitalization, tendency toward withdrawal). Self concealment was exemplified in responses such as, “...I had tricked my doctor into giving me a prescription for approximately 40 tablets of diazepam, which I used with alcohol and other medications in another failed attempt at suicide.” The subtheme *Symptoms* included responses such as, “It was not always smooth sailing and since I was paranoid it took a while to build up trust and accept treatment.”

Table 18

Dimensions of Theme Seventeen – Barriers to Recovery: Internal Inhibitors

| Theme | Subthemes |
|--|---|
| Barriers to Recovery: Internal Inhibitors | 1. Medication-related 2. Self concealment 3. Symptoms |

Effects of internal inhibitors. Table 19 depicts the subthemes within *Barriers to Recovery: Effects of Internal Inhibitors*. I defined this theme as “any reference to the type of negative effect resulting from the diagnosed individuals’ actions and/or aspects related to his/her self-experience preventing and/or delaying the diagnosed individual from engaging in the process or experience of recovery.” The subtheme *Relational* may be seen in responses such as the following:

At this point I did not believe my mother was my real mother and I again anticipated being the subject of medical experiments. I viewed the doctors and my family as spiders waiting to pounce. Subsequently, I did my best to protect myself and the ideals of the resistance to which I adhered.

The subtheme *Functional* referred to deficits in skills required for engagement in purposeful activities, including occupational activities, captured in responses such as, “I have found that, under the shackles of the illness of schizophrenia, taking the initiative to make important and even simple decisions in life can be especially crippling and sometimes paralyzing.”

Table 19

Dimensions of Theme Eighteen – Barriers to Recovery: Effects of Internal Inhibitors

| Theme | Subthemes |
|---|--------------------------------|
| Barriers to Recovery: Effects of Internal Inhibitors | 1. Relational 2. Functional |

Discussion

Overview

In this section, I discuss and interpret the major findings and highlights of the study and compare and contrast the results with existing models of recovery, with particular attention to the medical and consumer/survivor models. I provide recommendations for an integrated treatment model to promote recovery in schizophrenia in clinical practice. I address implications for graduate-level training and curriculum. Additionally, I discuss limitations of the study and provide recommendations for future research.

Recovery-Facilitating Frameworks of Care

Approaches framing recovery and/or general mental health treatment that emerged from participants mirrored key elements from SAMSHA's (2004) recommended approach to recovery as well as consumer/survivor and explicit recovery-oriented systems of care. Specifically, approaches were marked by holistic and collaborative behavioral health care. The holistic element of care referred to the idea of multidisciplinary and interdisciplinary providers, both professional and not, providing a variety of support types. This element of the approach is inherently integrated as it accounts for the contributions and interventions from medical and psychological providers as well as that from natural supports (i.e., family, friends, supervisors, teachers). The collaborative aspect of care referred to the notion of shared decision-making in treatment, a prioritized aspect of more recently developed recovery-focused frameworks of care for schizophrenia, such as NAVIGATE (Mueser et al., 2015), where the voice of the diagnosed individual holds as much meaning and importance in determination of options as the providing professionals. The delivery of treatment is not linear and hierarchical but rather active and interactive, with the individual playing a primary role throughout the entire process. Even in

situations where the diagnosed individual is found not to be competent to make legal decisions for his or her care, the act of listening and interacting should remain. Trust and openness become compromised when the individual with schizophrenia is silenced. Thus, MHPs' expressions of openness and respect, through listening to their clients' experiences and insights, promote and incorporate recovery in treatment, and may improve outcomes (Frese & Davis, 1997).

Much of the scholarly literature emphasizes the importance of early intervention in the treatment of schizophrenia, specifically first-episode psychosis (Kam, Singh, & Upthegrove, 2015). However, early intervention was only noted by two participants as an essential component of the mental health care they received. Some possibilities may be drawn from the results as to why early intervention was either absent in participants' treatment and/or not emphasized as beneficial if received. For one, barriers to recovery preventing entrance into recovery, such as lack of illness detection and denial of symptom experience may lessen the time in the course of illness where early intervention would be effective. Re-entrances into recovery and symptom relapse may also minimize the effectiveness of early intervention if it was actually employed as a framework of care. Therefore, it is all the more imperative for providers to assess phase of illness to determine appropriate treatment. An integrated model of recovery in particular would allow for consideration of treating certain phases of the recovery process (Peer et al., 2007; Schrank & Slade, 2007; Spaniol et al., 2002).

Only four participants experienced an explicit focus on recovery in the mental health care they received. This finding is unsurprising given the fact that incorporating recovery concepts in mental health care and developing recovery-oriented mental health systems of care is still developing and not widespread (Hanlon, 2014). Only one participant, notably in 2016, detailed his personal experience of receiving mental health treatment delivered specifically from a

recovery framework, known as the “Recovery Champions” course. The main elements of this treatment were captured by the following:

Rather than giving up with life and the pain and difficulty of living with a mental health problem, people are encouraged to make a 1 year plan of their dream (as well as their nightmares as barriers), which could be travelling, writing a book, getting a dream job.

They then work backwards with a recovery coach from 9 months to 6 months to 3 months and finally 72 hours, so that they have a pathway and a map to achieve their 1 year dream.

This shifts what can be a negative experience into a positive one, where dreams, aspirations, and a good future are anticipated and planned.

Notably, a conversation about recovery is introduced as quickly as the mental health treatment, a strategy actively countering the notion that diagnosis is equated to prognosis. Rather, the message is one of hope for the future and that diagnosis does not determine an outcome of illness chronicity. This framework somewhat mirrors the approaches of mobile crisis teams and Open Dialogue by responding to primary concerns as speedily as possible (i.e., within the first 72 hours; Seikkula et al., 2003). Recovery is viewed as imperative and necessary as stabilization and safety. A recovery focus represents an attitude shift in mental health care that is still growing in the U.S., as the Recovery Champions course has only been delivered outside the U.S.

Coordinated Specialty Care (CSC), a new recovery-oriented treatment program for individuals with first-episode psychosis (Dixon et al., 2015), represents an example of that growing effort in the U.S. to change attitudes towards the care of serious mental illness, including pessimistic attitudes towards the possibility of recovery. Furthermore, the National Institute of Mental Health’s research initiatives, such as Recovery After an Initial Schizophrenia Episode (RAISE), make it possible to test the soundness and effectiveness of new CSC programs, like NAVIGATE

(Lucksted et al., 2015).

Supportive Functions Transcending Support Types: A Needs-Based Conceptualization

The notion that different types of external and internal support resources can provide both similar and different functions facilitating the diagnosed individual's recovery speaks to the broader and overarching theme of the results of this study—that is, it is not the role of the support (either person, approach, attitude, or idea) that matters inasmuch as the supportive function and quality facilitating recovery that the identified support provides. Providers from diverse disciplines, both professional and not, can provide a variety of different and unexpected beneficial functions to the diagnosed individual's recovery. Thus, it is most significant to the diagnosed individual that he or she receive the functions facilitating recovery regardless of who may provide them. The subthemes emerging from both functions of external and internal support, as well as gains from recovery, may be conceptualized as aligning with and reflecting Abraham Maslow's (1943) hierarchy of needs, as outlined by his theory of human motivation.

Maslow proposed five tiers of needs within his hierarchy thought to motivate human behavior. The first four tiers of the hierarchy, are conceptualized as basic needs and consist of (a) physiological, (b) safety, (c) love/belonging, and (d) esteem needs. Self-actualization, the fifth and top tier of the hierarchy, is understood as a higher order need (Maslow, 1943). In this study, for example, the content pertaining to the subtheme "Functions of External Support: Practical" (e.g., housing, financial support) satisfied the safety tier of Maslow's hierarchy and is a necessary support for schizophrenia recovery. Physiological needs, such as warmth, food, and water; are inherently thought to be satisfied by safety needs, such as shelter and financial support. The love/belonging tier is satisfied by relational functions, such as friendship, shared and mirrored suffering, and acceptance by others in recovery. Emotional changes as a result of

internal and external support in recovery may satisfy the esteem tier, such as experiencing increased pleasure, relaxation, improved well-being, and feeling more humanized. Although qualitatively different from emotions, psychological functions of external and internal support may also satisfy esteem needs, such as gaining insight into symptoms, experiencing symptom relief, and gaining motivation, as examples, to reach self-actualization.

Self-actualization, the fifth tier, is satisfied by the types of gains from recovery, ultimately made possible by the internal and external supports and their functions to varying degrees. This is how support and gains are different; the former is ultimately the conduit to the latter. Therefore, self-actualization may be understood as a combination of the gains made from recovery captured by the theme, “New Perspectives: Gains from Recovery.” For instance, an individual with schizophrenia may consider him or herself having achieved self-actualization after developing a newfound sense of purpose (“Meaning”), maintaining emotional stability (“Emotional”), demonstrating a new grasp on reality (“Psychological”), living independently (“Functional”), achieving personal success (“Achievements”), seeing relationships as important and worth treasuring (“Relational”), and/or communicating hope for recovery through personal disclosures (“Helping others”). Of course, some of these sample gains mentioned satisfy other needs of the hierarchy; the difference, however, is that these gains are part of a new self-actualized sense of being, made possible by the internal and external supports and their functions. Interestingly, one of the participants described how compassion-focused therapy facilitates satisfaction of Maslow’s hierarchy of needs in recovery from schizophrenia, implying the importance of understanding the comprehensive and multifaceted needs for diagnosed individuals in their experience of the illness and recoveries.

Facilitators and Barriers to Recovery: Two Sides of the Same Coin

It is highly important to acknowledge that external supports can serve as both facilitators and barriers to recovery from the perspectives of some participants. Those external supports include MHPs and the psychiatric approach. The quality and nature of MHPs is critical. Those MHPs who demonstrate qualities characteristic of agreeableness, such as empathy, respect, compassion, and sensitivity; as well as provide at least one of the multiple facilitating functions (e.g., practical, psychological, emotional, relational, functional, etc.) required for recovery by diagnosed individuals, will likely be well-received and accepted throughout the recovery process. However, providers who embody a domineering, disrespectful, and oppressive stance; and who silence and blame diagnosed individuals for their symptom and illness circumstances, may halt the recovery process from the very beginning. Although these kinds of interactions between providers and diagnosed individuals may seem unfathomable, all the factors that may lead to a professional engaging in less than helpful and even harmful behavior to their consumers of treatment must be considered (e.g., unprocessed countertransference, burnout, ignorance; Torgalsbøen, 1999). Additionally, MHP neglect or omission of information (e.g., lack of explanation for underlying medication decisions, absence of conversation with diagnosed individuals about auditory hallucinations) may similarly prevent diagnosed individuals from entering recovery. Moreover, at least one third of all participants noted some dissatisfaction with psychiatry as an approach and institution, specifically inpatient hospitals, pharmacological intervention, and the very diagnostic label of schizophrenia. Despite the common effectiveness of pharmacological intervention facilitating recovery (Buchanan et al., 2010), the inherent difficulty associated with the experience of taking medication is especially noteworthy.

Process of Recovery

Results of qualitative analyses indicated the process of recovery to be characterized as nonlinear and occurring in stages, consistent with the scholarly literature (Davidson & Roe, 2007; Peer et al., 2007; Spaniol et al., 2002). These results, however, revealed a phenomenological understanding of the non-linearity. The process of recovery's nonlinearity is a product of the changing nature of the illness course, particularly the re-emergence or exacerbation of symptoms. The variability in illness course is likely inherently related to the diagnosed individual's changing view and participation in the process of recovery and engagement with potential facilitators in the mental health system (e.g., medications, treatment approach, etc.). Moreover, changes in illness course and engagement in recovery ran parallel to the process associated with illness awareness and acceptance of illness circumstances, the latter of which is also consistent with the scholarly literature (Ridgway, 2001).

Although more than half of the participants referred to the recovery process as occurring in stages, stages were not consistently and clearly defined across accounts, again suggesting the individual paths of recovery. One reason for lack of definition may be due in part to when individuals consider themselves to have entered and/or re-entered recovery. Similarly, some participants noted the first stage to occur prior to their first hospitalization while others considered it to begin post-hospitalization. The difference in first stage start time likely spoke to the extent to which participants believed recovery could begin during or after some level of illness stabilization, implied by the use of inpatient treatment. Some regarded their entrance into recovery as evidenced by a change in attitude and approach to their lives rather than physical entrance into treatment.

Broadly, the second stage appeared characterized by active participation in treatment

while the third stage seemed to more explicitly address goal achievement and redefinition of the future. More relevant is understanding how diagnosed individuals define their stages of recovery. One participant's understanding of the stages as a course of "different realities" may exemplify this point as well. The transtheoretical model of behavior change (Prochaska & DiClemente, 1992) may be helpful in this regard in determining treatment options based on the individual's self-described stage of recovery (e.g., first stage marked by some denial of symptoms, synonymous to pre-contemplative stage of change).

Although results indicated the process of recovery to be ongoing or variable in nature, consistent with the literature (Davidson, 2003; Weiden, 2005), the sense that the process is long regardless emerged from the results and was not as apparent in the scholarly literature. Recovery, described by some participants as a "journey," was understood to occur slowly, gradually, and in small steps. For some participants, long length of time also characterized the process of illness awareness and acceptance as well as treatment acceptance. However, length of time should not be confused or likened to misconceptions of schizophrenia as ultimately chronic and recovery as impossible. From the perspectives of participants, rather, recovery is possible and the course of illness dynamic. Thus, it is important for practitioners to make this distinction for diagnosed individuals when providing them psychoeducation about course of illness and recovery, as well as to society at-large. Making such a distinction provides another opportunity for practitioners to both counter stigma associated with illness course and distinguish between diagnosis and prognosis.

Experience of Recovery

The phenomenological experience of recovery may be understood as multidimensional. For one third of study participants, the experience of recovery, both general and specific aspects

of it, was marked by a dialectic of seemingly opposing truths, emotions, and states of being (e.g., terror and safety, agony and ecstasy, illness suffering in service of a greater purpose). The complexity of the recovery experience sheds light on the reasons why it may be a process in general, and a difficult process at that.

Recovery as an overwhelmingly difficult experience for participants was especially enlightening and was often noted as “not easy,” “tough,” and a “struggle.” Most difficult was the impact of the illness itself on participants. From symptom relapses to facing and managing distressing voices, schizophrenia was found to take a toll on multiple aspects of participants’ quality of life, including occupational, relational, and general functioning. Recovery can be a lonely, devastating, uncertain, hopeless, and even scary experience. As such, the difficulty associated with recovering—in addition to the stress inherent in making big changes—has the potential to become a barrier to recovering at all.

Adding to the multidimensionality of the recovery experience was the variability among participants’ in their relationships to and utilization of different aspects of the recovery experience. Examples included differences among participants in paths to recovery, pharmacological effectiveness, mental distress, and personal storytelling. Such variability spoke to the individualized nature of each participant’s experience of recovery facilitators, regardless of the fact that most utilized similar treatment options. Thus, results implicated that recovery in schizophrenia is not a prescribed, one-size-fits-all treatment but rather a plate of options drawn from an entire menu of possibilities.

Meaning of Recovery

Qualitative results indicated that, from the perspective of individuals diagnosed with schizophrenia, the meaning of recovery is both multifaceted and individualized. Participants’

personalized understandings of recovery incorporate aspects from process, outcome, psychiatric rehabilitation, and recovery models (Anthony, 1993; Beeble & Salem, 2009; Davidson & Roe, 2007; Peer et al., 2007; Spaniol et al., 2002; Thornhill et al., 2004; Weiden, 2005;) as well as SAMSHA's clinical guidelines in the treatment and care of schizophrenia (SAMSHA, 2004), providing further support for the need to move towards adopting an integrated model of recovery in behavioral health care for schizophrenia. Definitions included symptom cessation, self-direction, achieving social re-integration, and self-actualization. Importantly, diagnosed individuals may incorporate one, some, or all elements of the existing recovery models in their definitions of recovery; some participants even explicitly identified with specific recovery models existing in the scholarly literature. The subtheme, "Normality (or something like it)," particularly represented a bridge between medical and process models of recovery, in that, despite the presence or absence of symptoms, the image of the diagnosed individual is thought to be no different from the typical, undiagnosed member of society at-large. However, achieving "normalcy," or the impression thereof, is only one of many types of recovery goals within a multi-dimensional framework. Other goals characterizing the meaning of recovery that resulted from this research included, but were not limited to, "knowing oneself under new circumstances" and, "learning to live again—and not just exist." Personal meanings and goals of recovery may also transform and evolve at varying times throughout the recovery process.

Implications of this research suggest that the goal should not be to reach a consensual definition of recovery, but rather to fully understand how each individual diagnosed with schizophrenia is constructing his or her own goals and meaning of recovery. Constructionism, then, serves as a framework for understanding how multiple definitions of recovery may exist and change based on diagnosed individuals' interactions with their supportive environments,

allowing for meaning making of the recovery experience not only by the diagnosed individual but in interaction with external supports. Additionally, by having a sense of breadth in options for types of recovery, MHPs are able to offer hope and ideas of potential meaning and goals to those diagnosed individuals presenting with hopelessness for future recovery.

Half of participants also reflected on their level of recovery, or “recovery status” at the time of the accounts. Results suggested that recovery status should be understood as occurring on a spectrum. Examples of different types of recovery statuses included having a “full” recovery, “being in” recovery, having an “almost complete” recovery, “not cured but improved,” and experiencing life as usual but “slightly more enlightened.” Participants’ varying degrees of recovery level achieved were consistent with the understanding that recovery goals may change throughout the process, especially if previously set goals are met. Other implications included the importance of participants being encouraged to write about their experience of recovery and illness at different points of the process, not just when they “achieved” their desired goals.

A unique contribution to the scholarly literature that emerged from the participant accounts was the notion that recovery can also signify contributing positively and constructively to society as well as influencing one’s surroundings for the better. This transcends the idea that recovery from schizophrenia must only pertain to individual goals and changes and likely relates to or underlies some individuals gaining the ability to help others as result of their recovery experiences and processes. The subtheme “Helping others” of “New Perspectives: Gains from Recovery” spoke to the importance various participants placed on serving as peer support workers; sharing their personal stories, both orally and through the written word; and communicating understanding of the suffering, hope for the future; and how to recover. It is unsurprising, then, that the presence of social support emerged as a key facilitator of recovery for

over half of the participants. The significance of both receiving and providing peer support has implications for individuals diagnosed with schizophrenia to have the opportunity to *be* peer supports to other diagnosed individuals, potentially in the form of peer support workers.

In addition to peers, social support in this study included family members, friends, and romantic partners. Although social support is identified in the scholarly literature as important to the experience and process of recovery for individuals with schizophrenia (Gumley & Clark, 2012), this study offered insights as to how this type of support is accomplished. The mechanisms by which support was delivered by family, friends, and romantic partners to participants included, but was not limited to, offering general support for the individual's continued recovery journey, such as hoping and believing in recovery and even serving as the reason for the individual's entrance into recovery; offering mentoring and advice on various matters, such as effective coping; providing psychoeducation about schizophrenia and facilitating illness awareness and acceptance of illness circumstances; being present during all or parts of participants' treatment, including inpatient psychiatric hospitalizations and various psychotherapy experiences; providing practical support (e.g., financial, assisting with grocery shopping); socializing as a means of distracting from illness; and showing care, love, encouragement, and empathy for the experience of schizophrenia. Supportive others, then, may be viewed as critical to the integrative mental health care of individuals with schizophrenia as other psychological and psychiatric services.

Recommendations for Clinical Practice

Based on best practices offered by existing models of recovery and emergent views of recovery from study participants, recommendations for applying an integrated model of care to the treatment of schizophrenia in clinical practice are offered. Recommendations for a model of

care facilitating recovery are separated into two categories: Integrated Assessment and Therapeutic Approach and Ongoing Interventions.

Integrated assessment. An integrated assessment may include the following components:

Stage of illness and recovery. An assessment of what stage the diagnosed individual is in with respect to both illness and recovery may elicit the diagnosed individual's personal understanding of illness experience and level of illness awareness and acceptance. If the diagnosed individual also identifies as being in some stage or phase of recovery, this portion of the assessment would seek to understand what constitutes that particular stage of recovery according to that individual.

Readiness assessment and re-visiting goals. MHPs should assess the diagnosed individual's readiness to participate in discussions related to recovery and have an approach to overcoming barriers to these conversations. Qualitative results suggest that use of the transtheoretical model (Prochaska & DiClemente, 1992) in treatment would be helpful, as well as motivational interviewing, to assess readiness to engage in recovery and goal setting conversations. This model would also assist in evaluating what diagnosed individuals, already in the process of recovery, still want to achieve as evidenced by hopes for recovery and desired revision of goals. Results indicated that diagnosed individuals' goals for treatment and recovery may change and that individuals can want more, particularly after achieving initial goals. Individuals may still have hopes for more even once recovery expectations are met. Thus, it is important for the specific interventions to match the diagnosed individual's level of contemplation and potential ambivalence about entering the recovery process. Moreover, assessing readiness continually and re-evaluation of goals helps MHPs keep current in our own

expectations of the diagnosed individuals we treat.

Strengths-based assessment. This assessment is one that evaluates the ways in which diagnosed individuals have already helped themselves in service of achieving preferred goals (e.g., alleviating symptoms, rebuilding relationships). Examples of strengths promoting recovery from the study included, but were not limited to, participants' use of self-strategies, reflection, and agency to promote recovery; as well as qualities characteristic of extraversion (e.g., resilience, courage, motivation, determination). A strengths-based assessment reflects and aligns with aspects of recovery models promoting individual strengths and qualities in coping with and transcending mental illness (Schrank & Slade, 2007; Davidson & Roe, 2007).

Needs assessment. Conducting a needs assessment with the diagnosed individual, as framed by Maslow's hierarchy, may reveal what beneficial functions of external and/or internal support the individual is already receiving and where the gaps in needs still exist. This provides guidance for interventions.

Therapeutic approach and ongoing interventions. A therapeutic approach and integrated framework of interventions promoting recovery may include the following components:

Multifaceted and welcoming approach. Diagnosed individuals may benefit from an integrated and non-monolithic approach that is holistic, collaborative, and recovery-focused. Currently, such an integrated model of mental health treatment for schizophrenia is best exemplified by CSC programs, such as NAVIGATE. Additionally, an inviting, non-threatening, and non-stigmatizing therapeutic stance and mental health setting (e.g., hospital, outpatient therapy office) may prevent diagnosed individuals concealing illness symptoms from providers. This way, individuals are less likely to compromise their own ability to engage in recovery, and

rather, be encouraged to share their experiences of schizophrenia. Moreover, this type of environment prioritizes the voice of the service user in shaping recovery by having an explicit and open dialogue about what recovery means to the individual.

Listening to the voices of the voice hearers. Religion, faith, and spirituality were key facilitators of recovery for at least one third of study participants, consistent with the scholarly literature concerning the benefits of spirituality in recovery-oriented care for psychiatric disorders (Huguelet et al., 2016). Thus, it is critical for practitioners to assess the extent to which the voice of God or other faith-based figure, sometimes understood as a religious delusion or hallucination in the context of a schizophrenia diagnosis, is underlying the diagnosed individual's entrance into and/or participation in recovery. A culturally sensitive practitioner is not only understanding of the diagnosed individual's symptom experience from relevant cultural or spiritual traditions but also evaluating how symptoms may be in any way functioning as strengths and facilitators. Although symptoms were often found to be distressing and terrifying among the majority of study participants, exceptions must be considered where the voices are encouraging entrance into treatment and/or serving as a source of support in recovery.

Recovery as initial concept. The concept of recovery—or whichever term the diagnosed individual prefers or is receptive to—may be introduced alongside illness psychoeducation and treatment options, rather than later or never. An integrated recovery model may be implemented at the very outset of therapeutic contact with the diagnosed individual regardless of the behavioral health setting. The readiness assessment provides a way for MHPs to determine appropriate timing of orientation to the notion of recovery, as some study participants presented with clear barriers (e.g., disorganized thoughts, paranoid delusions) to engaging in recovery at various times during the process. However, it is similarly crucial to not underestimate the

diagnosed individual's ability to engage in *some* form of a recovery dialogue, as goals for recovery can range from presumably major (e.g., symptom cessation) to seemingly minor changes (e.g., finding hope). The smallest but most meaningful unit of change that the diagnosed individual identifies can be considered a kind of recovery pursuit. In his organization's use of Program for Assertive Community Treatment (PACT) and the Open Dialogue approach, Ross Ellenhorn, Ph.D., does not even use recovery language, citing how many diagnosed individuals have suffered "psychosocial damage" due to mental health treatment (Ross Ellenhorn, personal communication, August 4, 2016). Instead of asking about recovery, Dr. Ellenhorn seeks to understand where individuals want to go and helps them get there. Thus, the process of recovery can begin at first therapeutic contact, particularly at first hospital admission and not after it.

Psychoeducation about multiple etiologies of illness. Dependent on the diagnosed individual's level of readiness, psychoeducation about the various etiologies of schizophrenia (e.g., biological, biopsychosocial, cognitive, psychodynamic, cultural) as supported by a constructionist framework, may be helpful in both increasing personal illness understanding and acceptance and engagement in recovery processes. Creating narratives of recovery is a process of meaning-making; part of that process is understanding how illness came to enter the individual with schizophrenia's life. Several participants offered possible theories for symptom experience; these ideas have the potential to be supported and validated by MHPs efforts to offer etiological frameworks and illness case conceptualizations with service-users.

Personal meaning of recovery. Diagnosed individuals' personal definitions of recovery are critical to not only treatment but life goal setting. Thus, MHPs should afford ample clinical time to fully listening to and understanding diagnosed individuals' conceptualizations of personal recovery. If diagnosed individuals do not have the knowledge or capacity to provide

their own recovery definitions, providers should offer and illustrate examples and possibilities of recovery definitions and statuses based on existing theoretical understandings of recovery as well as narratives of those who have written/spoken about their experiences, such as those that were the focus of this study. IRT, one of the four treatments provided by the NAVIGATE early intervention program, devotes an entire module to exploring the individual's definition of recovery and providing written examples of how other individuals have defined it (Penn et al., 2014). Imagine yourself as an MHP sharing a personal recovery definition from a *Schizophrenia Bulletin* first person account with an individual diagnosed with schizophrenia who has never heard of recovery associated with illness, nor thought it was possible.

Sharing and empowering voices. Diagnosed individuals would benefit from having access to personal stories of experience and recovery from other individuals diagnosed with schizophrenia. Personal accounts from others may offer illness understanding, ways to recover, and a general sense of empathy for the experience of schizophrenia. Individuals diagnosed with schizophrenia should be able to read and hear the stories of service users just as much as the same diagnosed individuals should have the opportunity to share their own narratives with the world, particularly MHPs. External supports should encourage diagnosed individuals to document (e.g., write, speak, draw, record) their experience of recovery throughout multiple points of the process, during times of both struggle and achievement. Narration at varying points of the process illustrates the natural richness and complexity of the process and experience of recovery from schizophrenia, ultimately enhancing self-understanding, and better awareness of individual experiences for MHPs. Opportunities to receive peer support should also be a key aspect of service delivery. Diagnosed individuals' should be evaluated for their willingness, readiness, and ability to effectively provide peer support to others with schizophrenia.

Hold hope. An appreciation and patience for the length and difficulty often associated with the process and experience of recovery is key. Practitioners need to be validating, empathic, and patient with the struggle, and need to help diagnosed individuals make sense of their struggles in the service of achieving stated aims to prevent self-discouragement and ultimate withdrawal from the recovery process.

Elicit feedback. Almost half the participants included a “Call to Action,” subtheme of “New Perspectives: Reflections from Recovery Experience,” in their personal accounts, a type of charge for providers and the behavioral health system at large to undertake and make change. Calls to action ranged from improvements in service delivery, provider approach, and illness education and understanding, particularly to combat stigma; as well as integration and balance of epistemological perspectives on schizophrenia and recovery, redefining what constitutes as valid knowledge in informing treatment. The very inclusion of calls to action in participant accounts suggests an overarching need to empower diagnosed individuals to provide feedback to their providers as well as elicit feedback from diagnosed individuals continually at every level of care (i.e., outpatient, intensive outpatient, partial hospitalization, and inpatient). Feedback and reflection from individuals with schizophrenia are essential in guiding care and recovery goal planning.

Self-reflective practice. Though the majority of MHPs are taught to engage in self-reflective practice and assessment of biases that may negatively impact patient care, multidisciplinary teams treating individuals diagnosed with schizophrenia would especially benefit from routine self-reflective practice as a group. This practice may help prevent the occurrence of recovery barriers that were noted by some participants to emerge from the psychiatric approach. For example, the majority of study participants experienced at least one

psychiatric inpatient hospitalization, a stay that often preceded the diagnosed individual's active pursuit of recovery. Complaints made of psychiatric inpatient hospitals included, but were not limited to, lack of therapy and general compassion in therapeutic interactions, restriction to outlets for coping, and lack of safety instilled on the units. Effective pharmacological intervention was both lacking and delivered coercively in such settings as well. Such areas of potential deficit or weak care serve as discussion points for care teams to reflect upon, to see if they are providing such care and not just focusing on discharge aftercare. Inpatient treatment, generally, needs to improve by providing treatment and not just stabilization. This is where the intervention begins, not afterwards. To this end, eliciting feedback from diagnosed individuals both verbally and through formalized outcome questionnaires/rating scales would be beneficial.

Recommendations for Graduate Training in Clinical Psychology

Just as providers should equally incorporate recovery, medical, and psychosocial approaches to care according to relevance and service-user preference, so should graduate training program curriculum include recovery-oriented practice alongside, medical, psychological, and psychosocial interventions. A first diagnosis of schizophrenia provides a critical choice point for MHPs to reclaim diagnosis apart from prognosis; MHPs may conceptualize and clinically treat the client in a manner that may influence the course of illness quite positively. For example, the use of medication may be better employed shortly after first diagnosis, influencing a better course, but perhaps less optimal for treatment of possible, future psychotic episodes, based on the finding that, "positive psychotic symptoms in a first episode psychosis, as compared to repeated episodes, are more likely to respond to antipsychotic pharmacotherapy" (Addington & Addington, 2008, p. 368). Providing optimal guidance for efficacious implementation of interventions, based on time of illness onset and illness course,

should be routine in graduate training. Such teachings emphasize and aim to ensure best practice in the mental health field.

Similarly, graduate trainees should receive education in courses pertaining to serious mental illness about the consumer/survivor movement in conjunction with other historical understandings of and treatment for schizophrenia. Specifically, trainees should be armed with a working knowledge of service-user definitions of recovery as well as common aims and goals of recovery. Assigned course readings should include first person accounts of serious mental illness and recovery. As trainees have been found to be less optimistic about the prospect of recovery in serious mental illness (Roe, Yanos, & Lysaker, 2006), incorporation of the recovery perspective in curriculum and training is thought to raise optimism among trainees and encourage future clinical endeavors with those who have SMIs. Training should also include instruction, even role-playing, on the actual nuts and bolts of delivering an integrated approach to individuals with schizophrenia in practice, focusing on helping diagnosed individuals understand the plethora of potential recovery agents that will depend on that individual's preferred plate of options.

Of course, a preferred agent of recovery is only as good as its access. Socioeconomic status, environment, culture, and social support all play a role in dictating whether or not diagnosed individuals may access and take advantage of preferred options. An understanding of these limitations to access should be embedded in graduate courses pertaining to issues of social justice, advocacy, and public policy; with knowledge of how trainees may influence these systems to effect change. For example, trainees may receive education about how to explicitly make efforts to bridge the gap between the outcome and process models of recovery in their practica, emphasizing the freedom and benefit of multiple interpretations of recovery. Relatedly, opportunities for practica pertaining to the treatment of SMI should be increased. Although

organizations, like the National Alliance on Mental Illness (NAMI), already exist and carry out missions of social justice, Ackerson and Korr (2007) encourage involvement from MHPs, which may include trainees. As both internal and external stigmatization may deplete a diagnosed individual's hope for recovery and subsequently interfere with the process (Anthony, 1993; Shean, 2009), anti-stigma movements are necessary to transform numerous misinformed and negative societal attitudes towards schizophrenia (Paquette & Navarro, 2005).

Results showed that individuals with schizophrenia see stances of agreeableness as most helpful and recovery-inducing. Therefore, training should heavily emphasize the importance of this stance by debunking many stigmatizing myths about schizophrenia that interfere with practice. Having trainees be very forthcoming from the beginning about biases they may have or know of will lay the groundwork for how the course material and discussion can reshape perspectives that may be otherwise treatment interfering and ultimately inform the practice of these future practitioners in a positive way. By replacing old views of chronicity, for example, with recovery-oriented notions, trainees are afforded the freedom to consider a number of viable treatments beyond medication, and in collaboration with their clients. In this regard, differentiating diagnosis from prognosis may diminish trainees' biases and negative attitudes towards recovery, if they exist, ultimately improving therapeutic alliances and treatment probability.

Limitations of the Study

Methodological limitations. A narrative analysis of written accounts does not allow clarification of meaning of participants' statements as do interviews. As such, analysis and interpretation of this research was limited to the explicit content in the writings of individuals with schizophrenia. As the accounts are brief, limited by *Schizophrenia Bulletin's* rules for

manuscript length, it is beyond the boundaries of this research to infer what content and details may be missing. Similarly, the amount of accessible demographic and contextual information of participants was limited to the content of the written accounts and not uniformly included across accounts.

Constraints of generalizability to select populations. Over half of the research participants had at the very least spent some time in undergraduate school either before or after illness onset, or both. As such, a largely college-educated sample raises questions about the generalizability of findings and access to resources promoting recovery to those who may be of a lower level of literacy and social and socioeconomic status. Relatedly, *Schizophrenia Bulletin* requires submission of first person accounts through their web-based manuscript system, implying that only those diagnosed individuals who have access to the internet, or received support in submission from individuals who do have internet and computer access, were able to offer their narratives. Thus, the research sample is inherently limited to those who have voice and some level of access to resources, including vehicles of expression, making the group of participants quite select. Additionally, a handful of the personal accounts were written by individuals from other countries, suggesting potential cultural differences accounting for any part or all of their recovery experiences. Although a limitation in terms of potentially generalizing to U.S. mental health care as it stands, it is a potential strength of the research in terms of encouraging the U.S. to adopt practices that have been beneficial cross-culturally for individuals with schizophrenia.

Suggestions for Future Research

In light of the fact that some participants were from other countries and cultures, it would be beneficial to compare and contrast the process, experience, facilitators of, and gains from

recovery between those diagnosed with schizophrenia in the U.S. and those diagnosed individuals from other countries—including developing countries—as research suggests better recovery outcomes cross-culturally than in European cultures (Jablensky et al., 1992). As many of the participants were also purportedly college-educated, future research should focus on asking individuals with schizophrenia of varying socioeconomic statuses and levels of education about their experiences of recovery in schizophrenia, particularly with respect to the five factors of recovery that emerged from this research. Schizophrenia as an illness does not exist outside of societal, racial, cultural, political, and economic issues. Serious disparities exist in access to mental health care and adequate insurance coverage for individuals with schizophrenia based on, for example, geographic location, ethnicity, and socioeconomic status (Versola-Russo, 2006). The results of this research do not speak to these diversity factors that are critical and foundational to having any comprehension about the conditions individuals with schizophrenia continually face in their lives, particularly with respect to illness experience and recovery.

Other ideas for future research include studying the extent to which the five factors of recovery resulting from the current study are relevant to the experiences of individuals with first-episode psychosis. What factors, with respect to the five resulting from this study, may be critical to facilitating recovery in this vulnerable population? Relatedly, how do these factors of recovery function across the lifespan for individuals with schizophrenia? Are some more important than others at different developmental times? Even more, in what ways may practitioners capitalize or utilize these factors for individuals in the prodromal phase of illness? All these questions are of future concern.

Additional research may explore the degree to which an individual with schizophrenia's creation of a coherent recovery narrative may actually facilitate and promote recovery, as well as

what primary and common factors (e.g., education, literacy, culture) enable a person to develop those narratives in general. Research investigating the therapeutic gains that may result from writing about experiences of recovery, versus other modalities of narration, and the effects of creating a metacognitive narrative, would be optimal in this regard. The majority of participants' narratives were also retrospective and written after varying lengths of time with respect to their illness experiences and recoveries. However, a few were written while the individual was in some form of recovery. Therefore, it would be fruitful to research the extent to which the timing and form of narration of illness and recovery experience may actually promote or facilitate recovery. What are the potential benefits of creating the narrative at the very beginning of the recovery journey rather than at the end or in hindsight?

As new questions may often emerge from the analytic process in narrative research (Riessman, 1993), it is important to highlight the questions and new insights that were not of focus during the outset of this research. First, the following research question emerged from the analysis during this study: what is the experience of recovery like for individuals diagnosed with schizophrenia? Importantly, qualitative research has tended to focus on the experience of schizophrenia from diagnosed individuals' perspectives much more than their perspectives on personal experiences of recovery. Thus, future research should aim to seek a more phenomenological understanding of recovery as an experience. As most participants referenced a telling of their illness story in the context of recovery, research seeking to understand how, if at all, the experience of schizophrenia relates to and/or informs the experience of recovery may facilitate professional understanding with respect to treatment. Second, a new insight that emerged from this research was the sense that the process of recovery and experience of recovery, though not mutually exclusive, need to be researched and discussed as specific entities.

Finally, more scholarly research is needed to better understand the stages of schizophrenia both phenomenologically and qualitatively so new interventions that uniquely target the phases of the recovery process may be developed (e.g., most efficacious interventions for phase(s) involving illness awareness/acceptance and/or acceptance of illness circumstances).

I embarked on this research with the goal of creating a consensual definition of recovery; what I left with was an awakening about the importance of the individual perspective of recovery; and how that may be witnessed and shared among providers, loved ones, and other individuals with schizophrenia alike. Entering the worlds of these individuals with schizophrenia through their writings has been a privilege and humbling opportunity, an attitude that can easily translate to all in-person interactions with service-users in a variety of mental health settings. This research has afforded me the opportunity to become ensconced in many and diverse understandings of illness experience and recovery, making me all the more enlightened and hopeful for the futures of individuals newly diagnosed with schizophrenia. Having an integrated understanding of recovery in schizophrenia also instills hope and flexibility with respect to all the different ways providers may employ their skills and services to help diagnosed individuals. My ultimate hope is that this research turns the attention of the academic and professional mental health community to the voices of individuals with schizophrenia; we need to listen to and learn from them in order to be most helpful.

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Appendix

Codebook

1. Agents of Recovery: External Support Approach

a. *Definition:* Any reference to a framework or approach of mental health care that is viewed as beneficial to, preferred by, and/or facilitates recovery for the diagnosed individual.

b. *Sub-themes:*

i. Holistic

1. Example: "Being able to be in a private recovery center was the conduit to recovery. Having connections to housing services, higher education and education grant monies, to employment, to obtain SSI and Medicaid were instrumental. Getting a job in psychiatric research has been vital. Recovery involves the support of family, government, community, and beneficial psychiatric services. Recovery is not just one element, but rather many elements that lead to the wheel of health."

ii. Collaborative

1. Example: "Service users should be central to decision making about their own care and treatment because working in partnership leads to better outcomes for service users and their families."

2. Agents of Recovery: External Support Type

a. *Definition:* Any reference to a type of support, associated with the mental health field or not, that is viewed as beneficial to, preferred by, and/or facilitates recovery for the diagnosed individual.

b. *Sub-themes:*

i. Case Management

1. Example: "Help may be needed to support basic needs like cooking, keeping clean, and other household tasks. Giving and receiving practical support are inherently related to our care-giving mentality."

ii. Psychological

1. Example: "I started seeing another psychiatrist outside the hospital who fortunately was very caring. He listened to me patiently, got me on the right dose of medication, and after 6 months diagnosed me with schizophrenia. He described to me what the illness was and gave me literature references to read to help me understand the illness."

iii. Pharmacological

1. Example: "I have been taking Zyprexa for three years, and it seems to be working beautifully, except for the extra twenty pounds of fat I'm carrying around. However, I wouldn't change it for anything. I have continued to notice steady improvement in my condition over the last three years, both for positive and negative symptoms."

iv. Provider

a. Mental Health Professional

1. Example: "My psychologist noticed that when I talked about some of my books and issues I knew about, I became much less terrified and able to think more clearly. This motivated me to write again and set goals."

b. Non-Mental Health Professional

1. Example: "I found others as well, leaders and guides, who gave me valuable advice on how to live. One was Christian writer C. S. Lewis. He said, 'What a sad world it would be with no one to look up to.'"

v. Social

1. Example: "I cannot stress the importance of having a supportive family and girlfriend during my time in the psych ward. My family was first in helping me come to realize that I suffered from schizophrenia. The book, *Diagnosis Schizophrenia*, which my family gave me, was particularly helpful."

vi. Religion/Spirituality

1. Example: "Almighty was slowly helping me and making me a brilliant researcher and teacher."

3. Agents of Recovery: Agreeableness of External Support

a. *Definition:* Any reference to agreeableness, a personality characteristic understood by the Five-Factor Model, demonstrated by a support type that is viewed as beneficial to, preferred by, and/or facilitates recovery for the diagnosed individual.

1. Example: "Oppressive doctors or therapists were not helpful, but the ones who respected my efforts at recovery were. Case workers were there for social support and advice."

4. Agents of Recovery: Functions of External Support

a. *Definition:* Types of results and functions, both intended and not, of any support types identified that are viewed as beneficial, preferred by, and/or facilitates recovery for the diagnosed individual.

b. *Sub-themes:*

i. Practical

1. Example: "A female social worker assisted in getting me into a private psychiatric recovery center. I had a room to myself, which allowed me some peace. A worker for that hospital assisted my getting on SSI and Medicaid."

ii. Psychological

1. Example: "After psychotic episodes...my parents decided to try me on a new antipsychotic, this time Clozaril....it worked, and the negative symptoms lessened dramatically."

iii. Emotional

1. Example: "Along with food and daily visits from family and friends, music helped keep me relaxed, even when I was receiving messages from all around me. One song in particular helped to calm me down...I remember an attendant complimenting my taste in music, which made me feel like a person again."

iv. Self

1. Example: "A lot of effort, time, and thought went into my recovery. My team took excellent care of me while I made my way back to normality. These people found me, which enabled me to find myself."

v. Relational

a. Provided

1. Example: "Perhaps the most influential has been meeting regularly with my supervisor, an anthropologist who studies the lived experience of psychiatric illness. She has aided my journey to recovery—by listening to my experience, often validating something I say...."

b. Achieved

1. Example: "Here, I met new friends who accepted me. My attention shifted to pleasure and was increased through meeting new friends..."

vi. Functional

1. Example: "Whilst having cognitive behavioral therapy, a support worker was put in place to go out with me, and I was gradually exposed to the fear I had of going out."

vii. Occupational

1. Example: "I was referred to National Institute of Mental Health and Neurosciences, Bangalore, India. I accompanied my parents to NIMHANS, Bangalore where we stayed in the family ward to be closely observed by doctors....we stayed there for 1 month as the new medication was administered. After treatment, we came back to Kolkata and I got a job as a researcher in one of the most reputed institutes of India."

5. Agents of Recovery: Internal Support Behaviors

a. *Definition:* Any reference to an action, or type of action initiated by the diagnosed individual, that is viewed as beneficial, preferred, and/or facilitates recovery.

b. *Sub-themes:*

i. Self-strategies

1. Example: "I felt hope for the first time in so long. I learnt to cope with my symptoms and implement strategies to reduce them."

ii. Reflection

1. Example: "After sometime reflecting and regrouping, I was determined to find a meaningful job and contribute positively and constructively to society."

iii. Agency

1. Example: "Joan of Arc has proven the perfect role model for how to live with faith as a schizophrenic patient. Even though her experiences were admittedly delusional, her life has demonstrated the power of faith. Although others, even during her own life, did not believe in what she had seen, she still had been able to arrive at a state of being in which she exercised a profound effect on others. I have taken the lessons of her life and applied them to my own, to live an inspiring life upholding belief and the spirit and to live for a cause other than purely one's own self-interest."

6. Agents of Recovery: Self-extraversion

a. *Definition:* Any demonstration of extraversion, a personality characteristic understood from the Five Factor Model, by the diagnosed individual that facilitates recovery and/or moves the individual to attain his/her aims associated with recovery.

b. *Sub-themes:*

i. Extraversion

1. Example: "But things took a turn for the worse when I was diagnosed with schizophreniform/schizophrenia. I pushed my way through."

7. Agents of Recovery: Functions of Internal Support Resources

a. *Definition:* Types of results and/or functions, both intended and not, of any actions initiated by and/or personality traits of the diagnosed individual that are viewed as beneficial, preferred, and/or facilitate recovery.

b. *Sub-themes:*

i. Psychological

1. Example: "Now the only thing left to get back in shape was my mind. I could barely concentrate for a few minutes, let alone the prolonged focus necessary to be a successful student at University of Michigan. To get back in shape, I decided that I would read *East of Eden*, quite a lengthy book and a rather ambitious goal for me at the time. During the beginning, I could only read a few pages at a time, but later, I was able to read entire chapters without losing focus. Eventually, my concentration went back to normal."

ii. Emotional

1. Example: "My search for alternative approaches to manage this illness has helped me stay in stable full-time employment (since 2005) and to improve my general well-being and happiness and avoid hospitalizations."

iii. Functional

1. Example: "I was changing jobs frequently due to my restlessness and anxiety. I thought judgment day will never come to my life. I was depressed, weak, and emaciated. Again, due to my resilience, I got a teaching job at a reputed engineering college."

8. Process of Recovery: Nonlinear

a. *Definition:* Any reference to aspects of the process of recovery that are nonlinear in nature.

b. *Sub-themes:*

i. Illness course

1. Example: "I have just spent a month in a psychiatric ward. In fact, as I write this, I'm still here. It's my third relapse in 10 years, and the first time it lasted for nearly a year."

ii. Views of treatment and participation in recovery

1. Example: "It took me a long time for me to admit to myself that I had been mentally ill, and that I needed to take some type of psychiatric medication for the rest of my life."

9. Process of Recovery: As Occurring in Stages

a. *Definition:* Any reference to aspects of the recovery process that are characterized as occurring as stages and/or descriptions of the stages associated with the recovery process.

b. *Sub-themes:*

i. Three Stages

1. Example: "I had a psychotic episode, and the treatment required medication in the hospital. Once that happened, I went to the next stage of my recovery."
2. Example: "Stage 2 lasted another 8 years. I became disillusioned with psychiatric professionals, and though I continued to see them for medication and counseling, I no longer respected them."

ii. Illness acceptance

1. Example: "At this point in time, I was in the early stages of acceptance and did not want to talk about my decisions and actions at all. Although I was struggling to accept my new reality (diagnosis etc.), I just spared a moment here and there to think about what life would be like to be mentally stable again. These ideas of being healthy gave me courage and this made me smile again."

10. Process of Recovery: Time Characterizing Recovery

a. *Definition:* Any reference to the quality of the time associated with the recovery process.

b. *Sub-themes:*

i. Ongoing

1. Example: "The last 10 years has not been easy. There have been hospital stays, numerous medication changes, and major lifestyle changes. All of that has brought me to today where I am in a state of constant recovery. I am fully aware that recovery never ends. As simple as it may sound: I must follow the rules of recovery. Not for the next month or 6 months, but for the rest of my life."

ii. Lengthy

1. Example: "Recovery to me was a mirage. Recovery was so slow."

11. Experience of Recovery: Difficulties Associated with this Experience

a. *Definition:* Any reference to types of difficulties associated with the experience of recovery.

b. *Sub-themes:*

i. Illness

1. Example: "I sometimes hear negative voices too. They can be insulting, and they can tell me to kill myself. This is part of the struggle. It's something I don't like to talk about. When I hear these negative voices, I do my best to stimulate my brain and be active, or I try to ignore them."

ii. Pharmacological Support

1. Example: "Zyprexa [sic] helps me tremendously....notwithstanding, I have gained so much weight I have to go off of it....Zyprexa makes me crave for food that is bad for me. I will sit down for a meal, and when I finish, oftentimes, I will start on another meal—something has to be done."

iii. Quality of Life

1. Example: "What proved hardest was to watch as my dreams died one by one."

12. Experience of Recovery: Multifaceted

a. *Definition:* Any reference to aspects of the recovery experience that are mixed, complex, variable, or individualized in quality and/or nature.

b. *Sub-themes:*

i. Dialectic of Recovery Experience

1. Example: "My illness, in and by itself, appeared to have destroyed me. But stepping back to see the broader picture, I saw that my painful trial of suffering had had a greater purpose. Though I continue to have setbacks and struggles, I am singing a song of a new and transformed life."

ii. Variability/Individual Differences in Recovery Experience

1. Example: "When one discovers how to live a life devoted to staying well, one discovers a peacefulness to life and serenity that once discovered is glaringly obvious, yet each path to that state is unique to each person."

13. New Perspectives: Gains from Recovery

a. *Definition:* Any type of positive change and/or gain resulting directly from the process of recovery.

b. *Sub-themes:*

i. Meaning

1. Example: "True, my illness had devastated me. It had crushed me in heart, mind, and spirit. The rebuilding of my life took time, 25 years in fact. But despite serious illness, I had found meaning."

ii. Emotional

1. Example: "My life seemed to take on new meaning and purpose. Things came to me naturally, and I really enjoyed what I was doing."

iii. Psychological

1. Example: "Why should I feel ashamed of who I am? The bad experiences and rough times came back in flashbacks. I didn't regret anything. They had made me who I am. I am enlightened."

iv. Functional

1. Example: "Since 2011, I am continuously on medication. I have had regularly recurrent episodes even then. However, they have increasingly been very short term (a couple of days at the most). I have never been hospitalized and live independently, even in a foreign country."

v. Achievements

1. Example: "I have actually had quite a lot of success in recent years. I joined my local volunteer fire department, and I was elected vice president this past year."

vi. Relational

1. Example: "I especially connected with a 70-year-old woman....recently, I took her with me to the chaplaincy group, where she said a little about herself and her 2 sons, which was the first group she had attended in some months. This helped us both a lot, and we have become good friends."

vii. Helping Others

1. Example: "The reason that I have written this essay is because I want to help others in similar situations, and by writing this all out I expand my awareness from the thoughts generated. I think this essay is crucial for both the learning disabled and mentally ill. All we want is a chance, a level playing field."

14. New Perspectives: Recovery

a. *Definition:* Any reference to new types of perspectives associated with any aspect of the concept of recovery that have largely resulted from the process and experience of recovery.

b. *Sub-themes:*

i. Assumptions

1. Example: "It is not easy, but ongoing victory is possible."

ii. Meaning

a. Multifaceted

1. Example: "'Recovery can mean many things,' I said. 'Recovery can be a process as well as an end. It is not necessarily the disappearance of symptoms, but the attainment of meaningful goals for one's life. Recovery means finding hope and the belief that one may have a better future. It is achieving social

integration. It is finding a purpose in life and work that is meaningful. Recovery is having clear direction.”

b. Normality (or something like it)

1. Example: “My illness has been abated, I am productive again, and I plan on having a normal existence for the rest of my life.”

2. Example: “Recovery to me means that, even if the delusions are not completely gone, I am able to function as if they are.”

iii. Hopes

1. Example: “I am now doing well in a way that is meaningful to me. I work, study and have recently gotten engaged to someone I met during recovery. I still take medication every day but I hope to not have to do this forever.”

15. New Perspectives: Reflections from Recovery Experience

a. *Definition:* Any reference to types of reflections and/or lessons learned as a result of the process and experience of recovery.

b. *Sub-themes:*

i. Necessary Facilitators of Recovery

1. Example: “Having a support network is essential to making a recovery to a normal life, and I have my wife to thank the most. I met her online in 2005, and she is always there when I am having trouble and need someone to center me.”

ii. Calls to Action

1. Example: “Involving service users in the development of the professional framework redefines the relationships between service users and professionals. In order to allow professionals to embrace the user voice, there must be a breakdown of the boundaries between professional knowledge and user expertise and recognition of both as blurred and incomplete. There must be a rebalance of power and a redefinition of what constitutes valid knowledge, whether it is derived from experiential, practice, or academic wisdom.”

iii. Awareness and acceptance of illness circumstances

1. Example: “My resilience increased throughout the [psychotherapy] sessions and by the time they finished I had a better opinion of myself and was able to understand that psychosis was an illness that could be treated.”

2. Example: “I was in denial about my mental illness for years. Now I accept it as a lifelong condition.”

iv. Recovery Status

1. Example: "Even now, I am not totally cured. But I have improved."

16. Barriers to Recovery: External Inhibitors

a. *Definition:* Any external source that prevents and/or delays the diagnosed individual from engaging in the process and experience of recovery.

b. *Sub-themes:*

i. Actions of Providers

1. Example: "My first doctor that I will call doctor A barely saw me and did not really talk to me. He just prescribed Risperdal with no explanation. If someone had sat me down then and spent a couple of hours for a couple of days, maybe I would not have had the type of problems that I had."

ii. Stigma

1. Example: "I believed that I had 'kicked' the disease. I even threw the remainder of my antipsychotics down the toilet in fear that a nosey visitor might notice them in the bathroom medicine cabinet and start making assumptions."

iii. Psychiatric Approach

1. Example: "Hospital wards can hinder recovery because the patients in [sic] and nurses are not sharing compassionate conversation and are left to watch the television. They do not always feel safe-like places."
2. Example: "More worryingly, when in hospital, violence is sometimes used as a tool for getting noncompliant patients to take their medication, usually via depot injection. This violence is often conceived of as right, as just, and in the patient's best interest. Certainly, many nurses I have spoken to have not only said that they do not like administering forcible injections but also say that they have a duty of care. Violence as care is an oxymoron and hides the institutionalized abuse of people with schizophrenia and mental health problems."

iv. Systemic Missteps

1. Example: "Daily evaluations by the psychiatrists were fairly simple, and I still do not believe they had any valid data on the actual details of my situation at the time."
2. Example: "I also began to believe that my phone was being tapped. My friends insisted I was mistaken. But no one knew enough to realize anything was wrong."

17. Barriers to Recovery: Internal Inhibitors

a. *Definition:* Any aspect related to the diagnosed individual's actions and/or self-experience that prevents and/or delays him/her from engaging in the process and experience of recovery.

b. *Sub-themes:*

i. Medication-related

1. Example: "During each psychotic episode, my family tried to get me medical help. Medications were prescribed, but I refused to take them. I didn't believe anything was wrong with me. I thought I was just having an unusual experience. I didn't want to take anything that altered my brain—those pills were for crazy people."

ii. Self-concealment

1. Example: "...I had tricked my doctor into giving me a prescription for approximately 40 tablets of diazepam, which I used with alcohol and other medications in another failed attempt at suicide."

iii. Symptoms

1. Example: "It was not always smooth sailing and since I was paranoid it took a while to build up trust and accept treatment."

18. Barriers to Recovery: Effects of Internal Inhibitors

a. *Definition:* Any reference to the type of negative effect resulting from the diagnosed individuals' actions and/or aspects related to his/her self-experience preventing and/or delaying the diagnosed individual from engaging in the process of experience of recovery.

b. *Sub-themes:*

i. Relational

1. Example: "At this point I did not believe my mother was my real mother and I again anticipated being the subject of medical experiments. I viewed the doctors and my family as spiders waiting to pounce. Subsequently, I did my best to protect myself and the ideals of the resistance to which I adhered."

ii. Functional

1. Example: "I have found that, under the shackles of the illness of schizophrenia, taking the initiative to make important and even simple decisions in life can be especially crippling and sometimes paralyzing."